

SPECIALIZED PEDIATRIC SERVICES REVIEW

REPORT OF THE
MINISTER'S ADVISORY COMMITTEE

April 2002

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SECTION I: EXECUTIVE SUMMARY

On November 5, 2001, the Minister of Health and Long-Term Care called for a provincial review of specialized pediatric services. This report provides the findings and recommendations of the Specialized Pediatric Services Review Committee (SPSRC), the provincial committee formed to provide advice to the Minister. The SPSRC included representation from the province's five academic health sciences centres (AHSCs) with specialized pediatric programs and the Ministry of Health and Long-Term Care.

This report provides a review and recommendations for the future delivery of pediatric cardiac surgery. As well, preliminary recommendations on pediatric organ transplantation are provided based on the information currently available.

The report builds on the considerable work done in the past on this topic, including the Health Services Restructuring Commission's (HSRC) provincial review of specialized pediatric services. The HSRC's report has been used by the SPSRC as a reference point for its work. The HSRC's major recommendations included: consolidation of pediatric cardiac surgery at The Hospital for Sick Children (if Children's Hospital of Eastern Ontario is unable to attain 200 annual cases); consolidation of kidney, heart, lung, and liver transplants at The Hospital For Sick Children for patients under 15 years old; and establishment of a pediatric coordinating group to develop guidelines to include minimum volumes for critical mass. The SPSRC updated the HSRC's data and analyses, which was based on 1995/96 data, to provide a current context upon which to base recommendations for the future delivery of tertiary pediatric cardiac surgery and pediatric transplantation services.

Several jurisdictions have recently studied specialized pediatric services, especially tertiary pediatric cardiac surgery. Section V provides an overview of information from Winnipeg and Bristol, England. As well, several recent research articles are highlighted. A recurring theme across jurisdictions is the positive relationship between volumes of procedures and favourable outcomes.

Highlights of the key observations and trends for pediatric cardiac surgery include:

- The incidence of congenital heart disease is expected to remain the same over time.
- The total number of surgeries is declining given that multiple interventions are now completed during one operation.
- The update to the HSRC analysis reveals a 12.2 % decrease in tertiary pediatric cardiac surgery between 1995/96 and 2000/01. (0 to 14 age group, excluding neonates)
- There does not appear to be any new data or research to support a change to the HSRC recommendations.
- CHEO's tertiary pediatric cardiac surgery cases have decreased since the HSRC review.
- LHSC's decision to discontinue tertiary pediatric surgery is consistent with national and international research and trends and supported by a province-wide review of the number of children requiring cardiac surgery.

Consideration of updated province-wide information, national/international trends, and current research led the SPSRC to make the following recommendations for the delivery of pediatric cardiac surgery in Ontario:

- (1) To ensure best outcomes, a coordinated system of tertiary pediatric services is required in the province and includes both surgical and medical services. The five academic centres should build on the experience of the SPSRC and commit to closer, collaborative relationships to effect this change and ensure access to specialized care.
- (2) Tertiary pediatric cardiac surgery should be centralized on one site with a targeted implementation date of April 2003. The recommended site is The Hospital for Sick Children.
- (3) Given that current medical practice recommends on-site surgical back-up for interventional catheterization procedures, pediatric cardiology using these methods, including immediate post-operative intensive care, should also be centralized at the same site, unless otherwise agreed to by members of the pediatric cardiac network (a medical forum proposed by Chairs/Chiefs not yet established).
- (4) The five AHSCs will collaborate with the Ministry of Health and Long-Term Care to make further recommendations on the provision of supports for families traveling greater distances for tertiary pediatric cardiac surgery.
- (5) To support the tertiary pediatric surgery program transfer and consolidation of these services on one site, a regional model for pediatric intensive care, including pre-operative and post-operative care must be developed.
- (6) Pediatric cardiac specialists in a tertiary pediatric setting should undertake tertiary pediatric cardiac surgery involving neonates and the 0 to 14 age groups.
- (7) The single site must be capable of providing service in both Official Languages.

For transplantation services, the following recommendations were made:

- (1) The Hospital for Sick Children should continue to be the sole provider of heart transplantation services for the pediatric population.
- (2) The Hospital for Sick Children should continue its role as the sole provider of kidney transplantation services for children aged 0 to 14 years, recognizing that London provides kidney transplantation for the 15 to 18 age group.
- (3) The SPSRC does not recommend a change to the delivery of liver transplantation services at the HSC and LHSC at this time. Program consolidation however, may be a future consideration for review by the proposed Specialized Pediatric Coordinating Council when it is established.
- (4) All other pediatric solid organ transplantation (e.g., lung, small bowel) should continue to be solely provided at The Hospital for Sick Children. The referring centres will continue to offer pre- and post-surgical transplantation care in a coordinated manner.
- (5) The proposed SPCC should give future consideration for a more in-depth review of provincial transplantation services with respect to considerations of quality of care, best outcomes and critical mass and pre- and post-surgical care. This review should extend to all hospitals offering pediatric transplant services.

Although the SPSRC process focused on provincial data, current research, and the expert opinion of the physician committee members, it also provided an opportunity for a group of

concerned citizens from Southwestern Ontario to meet with the SPSRC Chair and the SPSRC's London Health Sciences Centre representatives. The Southwestern Ontario Pediatric Parent Organization prepared a written submission, which was received and tabled with the SPSRC. Their submission expressed concerns with access and quality of care related to specialized pediatric programs, particularly the effect on residents of Southwestern Ontario caused by London's pediatric cardiac surgery program moving to Toronto. The SPSRC felt that the input was important and helped to make recommendations that take into account the impact on children and their families posed by traveling significant distances from home to receive highly specialized pediatric services.

To improve quality of care and health outcomes for Ontario's children, the SPSRC recognized the importance of strengthening the current delivery of care. To strengthen pediatric cardiac care, the five centres need to work together as a pediatric cardiac system, to utilize each centre in an appropriate role in the care of pediatric cardiac patients - this led to the recommendation for a regional model for pediatric intensive care, including pre-operative and post-operative care. Within this model, the lowest mortality rates and therefore, best outcomes will be ensured with the consolidation of the surgery component of pediatric cardiac care.

The report concludes with the recommendation for the creation of a Specialized Pediatric Coordinating Council (SPCC) for hospital-based specialized pediatric services. The SPCC would be advisory to the Ministry of Health and Long-Term Care and would provide an ongoing focus on the provision of highly specialized, tertiary and quaternary services for children. Initial membership would include the five pediatric AHSCs and a representative from Northern Ontario.

SECTION II: INTRODUCTION

On November 5, 2001, the Minister of Health and Long-Term Care called for a review of specialized pediatric services in the province. This report provides the findings and recommendations of the Specialized Pediatric Services Review Committee (SPSRC).

The CEOs and Academic Chairs/Chiefs of the five academic health sciences centres with specialized pediatric programs participated in the review. The centres are: Children's Hospital at Hamilton Health Sciences; Kingston General Hospital; Children's Hospital of Western Ontario at London Health Sciences Centre; Children's Hospital of Eastern Ontario (Ottawa); and, The Hospital for Sick Children (Toronto). The Ministry of Health and Long-Term Care participated through the Assistant Deputy Minister and the Executive Director, Health Care Programs as co-chairs. Also participating from the ministry were Regional Directors for the four regions above, and the Assistant Deputy Ministers of the Health Services and Integrated Services for Children divisions.

The SPSRC focused on highly specialized pediatric services including cardiac surgery, and kidney, heart and liver transplantation. This focus reflects the following realities: these tertiary types of cases are the most complex, are delivered by only a few hospitals, and have been previously reviewed by the Health Services Restructuring Commission (HSRC); the patient conditions addressed are life-threatening; specialized technology and skills and expertise are required to deliver services; and, patient outcomes have been studied.

A further impetus for the review was that the London Health Sciences Centre (LHSC) had reviewed a number of its programs and took a decision to divest several programs including tertiary pediatric cardiac surgery and pediatric heart transplant. Since November 2001, LHSC has not provided tertiary pediatric cardiac surgery or pediatric heart transplant – this coincided with the loss of their sole pediatric cardiac surgeon.

There has been considerable work done in the past on specialized pediatric services. From 1997 to 1999, the HSRC conducted a review of these programs in the province. The HSRC's report, Coordinating and Consolidating Specialized Pediatric Services in Ontario, February 1999, was provided to the Minister.

In its report, the HSRC recommended that pediatric heart, kidney and liver transplants for children under 15 years of age be consolidated at The Hospital for Sick Children (HSC), based on expert panel advice. It also recommended that tertiary pediatric cardiac surgery occur at HSC and Children's Hospital for Eastern Ontario (CHEO) and that should CHEO not achieve tertiary pediatric cardiac surgery cases of 200 annually, then consolidation of all tertiary pediatric cardiac surgery take place at The Hospital for Sick Children. (Further information on the HSRC process and recommendations is provided in Section IV of this report).

The HSRC's report has been used by the SPSRC as a reference point for its work. This allows for maximization of the considerable work completed to date. In evaluating the specialized pediatric services hospital system, the HSRC used data from the fiscal year 1995/96. The current review replicates the HSRC's analyses and updates the data to include all years between 1995/96 and 2000/01. As well, the current analyses include two additional age groups, namely newborns (0 to 28 days old) and children aged 15 to 18 years.

Reviewing the provision of specialized pediatric services is not unique to Ontario. Several other jurisdictions have studied and reviewed this issue recently. An inquest was commissioned in Manitoba in 1995 to review pediatric cardiac surgery in Winnipeg. In February 2001, it was reported that decisions were made in Denver, Colorado to change the configuration of pediatric surgery following a peer review of mortality rates. In England a major review was undertaken during 1998-2001 because of concerns with mortality rates in the pediatric surgery program in Bristol.

The SPSRC decided it was appropriate to use the HSRC work as a guide to reviewing the current provision of highly specialized children's services in Ontario.

SECTION III: SPECIALIZED PEDIATRIC SERVICES REVIEW COMMITTEE

(i) Terms of Reference

The terms of reference for the work of the SPSRC were developed as directed by the Minister of Health and Long-Term Care on November 5, 2001.

The SPSRC was asked to use an evidence-based approach to review: relevant models/experiences in other jurisdictions, the work of the HSRC and updated data related to its report; and, the current specialized pediatric services at the five tertiary centres for opportunities for coordination and collaboration.

The SPSRC was charged with formulating a set of recommendations to address the following areas:

- Future configuration of specialized pediatric services
- Programs requiring examination for potential to coordinate or consolidate through a network of pediatric services
- Mechanism(s) for ongoing collaboration.

The SPSRC confirmed the terms of reference at the first meeting. The full set is detailed in Appendix 2.

(ii) Work Plan

The Work Plan's activities permitted the SPSRC to meet its objectives in the timeframe requested.

The major elements of the workplan that the SPSRC deliberated in the five meetings included:

- reviewing the previous work of the Health Services Restructuring Commission (HSRC) as it related to the provision of specialized pediatric services
- reviewing updated data related to the HSRC's earlier findings and acquiring an understanding of this data and their trends in the current context. This was important so that the SPSRC could benefit from work already done and use it to assess the relevance of previous advice received
- reviewing further data and information on outcomes
- discussing key criteria for maintaining tertiary pediatric cardiac surgery services in the province
- examining critical mass, specialized skills and models for tertiary pediatric cardiac surgery
- developing recommendations for improving pediatric cardiac care and ensuring quality of pediatric transplant programs.

In addition, the SPSRC identified a number of other potential opportunities for coordination or consolidation through a network of specialized pediatric services and recommended a mechanism that would ensure ongoing collaboration.

(iii) Process

The process began with the Minister's announcement that he would invite the leaders of province's pediatric academic health sciences communities to advise him on the provision of specialized pediatric services.

The five meetings of the SPSRC occurred between December 20 2001 and March 5, 2002. All meetings and discussions were held *in camera* and all related material was transmitted on a confidential basis. This was a necessary requirement as the SPSRC was advisory to the Minister and it allowed the SPSRC to deliberate freely. Overall coordination was provided by ministry representatives from the Health Reform Implementation Team and the Toronto Regional Office.

The process did not allow for submissions or reviews by external parties. The SPSRC Chair received a letter from the Southwestern Ontario Pediatric Parent Organization (SOPPO) based in London, Ontario. The written submission provided by SOPPO was tabled and distributed to all members for discussion and information. The SPSRC Chair also met with representatives of SOPPO in London accompanied by the President and CEO of LHSC and the Chair/Chief of Pediatrics from the University of Western Ontario. The mayor of London also attended the meeting. At the meeting, SOPPO representatives expressed their concerns related to the provision of pediatric services in London, including the cost of centralization, quality and provision of care, parental concerns and child and community issues.

The SPSRC concluded its work in April 2002 and submitted its findings and recommendation to the Minister.

SECTION IV: HSRC REPORT -- HIGHLIGHTS AND RECOMMENDATIONS

In its review of hospital-based services in London, Toronto, and Ottawa, the Health Services Restructuring Commission (HSRC) identified the need to examine further, the provision of highly specialized, low volume pediatric services throughout the province. In 1997, the HSRC commenced a provincial review of specialized pediatric services. The review took 18 months.

The HSRC submitted the report Coordinating and Consolidating Specialized Pediatric Services in Ontario to the Minister of Health and Long-Term Care in March 1999. Similar to the process used for other HSRC advisory reports, it was submitted as confidential advice to the Minister. The HSRC website continues as an archival resource only and contains many of the reports generated by the HSRC during its four years of work. The report mentioned above is now available by linking to the HSRC through the Ministry of Health and Long-Term Care's website at www.gov.on.ca/health.

The HSRC report built on the recommendations of two groups the HSRC appointed, namely the Provincial Pediatric Task Force (PPTF) and an Independent Review Panel (IRP). The recommendations of the PPTF and IRP differ in several areas.

The PPTF was established by the HSRC in July 1997. Its mandate was to review program activity of tertiary and quaternary pediatric services which had potential for consolidation, to recommend the programs and services that should be consolidated, and the preferred sites for service delivery.

The PPTF membership included: Children's Hospital of Eastern Ontario; The Hospital for Sick Children; Children's Hospital at Hamilton Health Sciences; Kingston General Hospital; Children's Hospital of Western Ontario at London Health Sciences Centre; Windsor Hotel-Dieu; Thunder Bay Regional Hospital; Sudbury Regional Hospital; University of Toronto; University of Western Ontario; University of Ottawa; Queen's University; and McMaster University.

In December 1997, the PPTF made its recommendations to the HSRC, which included:

- existing configurations of tertiary and quaternary pediatric programs should be maintained;
- expansion of some facilities;
- a central provincial pediatric health network.

After receiving the PPTF's recommendation, the HSRC concluded that the mandate assigned to the PPTF had not been fully addressed. Specifically, the HSRC noted "the lack of conclusions about the need for appropriate critical mass and greater provincial coordination of highly specialized low volume pediatric services, could result in a lack of access to the best quality of care for these clients and potentially less-than-optimum child health outcomes".

The HSRC assembled an Independent Review Panel of three physicians from outside Ontario to review the recommendations of the PPTF. The IRP identified opportunities for consolidation of two services: pediatric cardiac surgery and transplantation. For pediatric cardiac surgery, the review panel recommended consolidation at two sites: The Hospital for Sick Children and Children's Hospital of Eastern Ontario. For pediatric organ transplantation, the IRP

recommended all kidney, heart and liver transplants for patients below 15 years of age be consolidated at The Hospital for Sick Children.

The IRP also recommended a provincial coordinating group accountable to the ministry to address the need for coordination and integration of specialized pediatric care.

The HSRC considered the advice of the PPTF and the subsequent recommendations from the IRP. As well, the HSRC reviewed the available literature on cardiac surgery and organ transplantation.

For cardiac surgery, the HSRC stated that published reports in pediatric and adult cardiac surgery clearly demonstrate a relationship between low procedure volumes and higher patient mortality rates. According to the HSRC, only The Hospital for Sick Children met annual minimum volume requirements for pediatric cardiac surgery.

For transplants, the HSRC cited research again to show positive relationships between the number of transplants performed by centres and patient outcomes. Risk of mortality is potentially higher in low volume centres than those performing a relatively high number for both heart and kidney transplants. Regarding concerns about the potential loss of local access that consolidation presents, the HSRC concluded that access to high quality care is a priority over local proximity. Greater benefit to children is provided by improved quality care resulting from consolidated services. This led the HSRC to the following recommendations:

- Consolidate pediatric cardiac surgery at two centres – The Hospital for Sick Children and Children's Hospital of Eastern Ontario
- Increase the tertiary pediatric cardiac surgery cases at Children's Hospital of Eastern Ontario to 200 cases annually and evaluate in 18 months – if CHEO does not achieve 200 cases then consolidate all pediatric cardiac surgery at The Hospital for Sick Children.
- Provide clinical rotations at The Hospital for Sick Children and Children's Hospital of Eastern Ontario for the London pediatric critical care residents to address teaching program requirements at London Health Sciences Centre.
- Consolidate kidney, heart, lung, and liver transplants at The Hospital for Sick Children for patients under 15 years of age.
- Establish a pediatric coordinating group to convene an expert panel to develop guidelines for these procedures; the guidelines to include minimum volumes for critical mass.

The HSRC data (1995/96) has been updated and presented in provincial volumes and facility-specific volumes are presented in Sections VI and VII of this report.

Pediatric Coordinating Group

The HSRC recommended a provincial coordinating group be established with a mandate as follows:

- Guideline development to ensure quality outcomes, minimum volumes for critical mass and possible consolidation of additional pediatric tertiary/quaternary services
- Providing expertise in evaluation of new procedures and technologies in specialized pediatric care
- Coordination of the development of outcome evaluation projects and standards of reporting
- Coordination of the development of information management systems for clinical information, outcomes and costs of pediatric care
- A collaborative network for directing patient referrals to tertiary centres
- Development of recommendations re the organization and coordination and planning of pediatric cancer services
- Review of transportation systems' ability to meet the needs of older pediatric patients and neonatal patients.

The HSRC recommended this group be accountable to the Ministry of Health and Long-Term Care, be supported by the Institute of Clinical and Evaluative Sciences (ICES) and establish partnerships with appropriate providers and other pediatric service organizations.

SECTION V: OTHER JURISDICTIONS

As noted earlier, a number of jurisdictions have reviewed the provision of specialized pediatric services. As well, the relationship between volumes of procedures and favourable outcomes has been studied in the scientific community and published, although the quality of evidence is not as high as the SPSRC would have desired.

The SPSRC refers to the HSRC's report for references on this topic. The SPSRC notes the following recent studies and events as an important context for its deliberations:

The Pediatric Cardiac Surgery Inquest Report was published in 2000 after the completion of the Chief Medical Examiner's inquest from 1995-1998 into the deaths of twelve children who underwent cardiac surgery in Manitoba. The inquest report concluded that:

"The available information suggests that the limited number of cases that can be undertaken in a province like Manitoba, with a population just over one million, represents an increased risk of morbidity and mortality, particularly in the case of high-risk surgery. Even if the catchment area were expanded, the base population would still not be large enough to support a full service program. The Inquest recommends pediatric cardiac surgery be re-initiated in Manitoba only as part of a regional program in Western Canada."

The Manitoba program has since formed part of the Western Canada specialized pediatric cardiac surgery program sited in Edmonton. The Western program includes workloads from British Columbia, Saskatchewan, Alberta and now, Manitoba.

In England, a public inquiry was conducted between October 1998 and July 2001. The October 2001 report of The Bristol Royal Infirmary Inquiry into the management of the care of children receiving complex cardiac surgical services provided 198 recommendations. Similar to the findings of the Manitoba Inquest, the Bristol Inquiry determined a relationship between low volumes of patients and higher morbidity and mortality rates. The Bristol Inquiry called for the development of "standards that should stipulate the minimum number of procedures which must be performed in a hospital over a given period of time in order to have the best opportunity of achieving good outcomes for children".

The Office of the Chief Coroner of Ontario investigated three deaths associated with the pediatric cardiac surgery program at London Health Sciences Centre (LHSC) and focused on a more detailed analysis of outcomes related to specific complex procedures. The Office of the Chief Coroner's report of November 2001 noted that after considering the factors of low volumes, human and equipment resources, the decision of the LHSC Board of Directors to discontinue pediatric cardiac surgery program was "entirely consistent with international trends in pediatric cardiac surgery where services tend to be centralized rather than decentralized. The decision is also consistent with the recommendations of the Royal Commission in Winnipeg which studied similar issues regarding pediatric cardiac surgery."

In January 2002, Canada's Premiers, with the exception of Quebec's, agreed to share human resources and equipment by developing Sites of Excellence for Low Volume Surgery in various fields, such as pediatric cardiac surgery and gamma knife neurosurgery. Quebec will share information and best practices. The Premiers recognized that some procedures are performed infrequently and that the necessary expertise cannot be developed and maintained in each province and territory. They have directed their Health Ministers to develop an action plan for implementation of such sites by August 2002.

Research undertaken by Hannan et al (Pediatrics, Volume 101, June 1998) studied 7,169 pediatric cardiac surgery cases between 1992 and 1995. It found that " ...even after controlling for patient age and several clinical risk factors in addition to procedure complexity (T)he maximal differentiation in mortality rates between high- and low-volume providers was at 100 procedures annually for hospitals and 75 procedures annually for surgeons. (However), in general, higher hospital volumes and higher surgeon volumes were associated with lower risk-adjusted mortality rates across all procedure volumes, so any decision to recommend minimum hospital or surgeon volumes for pediatric cardiac procedures should take into account this fact...".

This research has been recently expanded upon in an analysis by Chang and Klitzner of the effect of regionalization on outcomes for children undergoing cardiac surgery (Pediatrics, Volume 109, February 2002). Using a theoretical model, the authors predicted that of the 6592 cases studied "41 deaths could be avoided when all patients from low-volume hospitals were referred, and 83 deaths could be avoided when all patients from low- and medium-volume hospitals were referred to high-volume hospitals". They stated that "surgical mortality rates...became more stable and predictable when the annual case volume was greater than or equal to 170 cases/year" and noted that it has been shown with the adult population, "an economy of scale is achieved at an annual case volume of 200 to 300" and "believe that this conclusion may also apply to pediatric cardiac surgery".

SECTION VI: TERTIARY PEDIATRIC CARDIAC SURGERY

As a first step in reviewing the tertiary pediatric cardiac surgery data subset, the SPSRC reviewed data related to overall tertiary pediatric surgery (i.e., aggregate data that included pediatric cardiac surgery) performed in the province. This allowed the SPSRC to view any emerging trends in the surgical subspecialty in the context of province-wide surgical activity.

(i) Data Considerations

For their reviews, both the SPSRC and HSRC relied primarily on the databases available through the Canadian Institute of Health Information (CIHI).

The Canadian Institute for Health Information (CIHI) is a national, not-for-profit organization responsible for developing and maintaining the country's comprehensive health information system. Health care organizations, including hospitals, submit facility data to CIHI in order to develop tools to advance Canada's health policies, improve the health of the population, strengthen the health system and assist leaders in the health sector make informed decisions.

The HSRC examined "tertiary cases" as defined by Case Mix Group (CMG) and principle procedure, based on a complex and multifaceted algorithm developed by an independent consulting group. Further details of this methodology are presented in Appendix 5. In general, the CMG methodology is designed to aggregate patients with similar clinical and resource utilization characteristics and applies to acute care, inpatient stays only. Specific CMG codes are assigned to cases according to their most responsible diagnosis, complexity of care and age. The neonate age grouping (age 0-28 days) has its own CMG. CMGs are further divided into medical and surgical categories (major clinical categories, or MCCs). If a case is assigned to the medical MCC, a list of diagnosis codes (grouped according to similarities in length of stay and resource requirements) is used to assign the CMG. If a case is assigned to the surgical MCC, a hierarchical list of procedure codes is used to assign the CMG. The procedure codes are defined by the Canadian Classification of Surgical Procedures (CCSP). As an example, in order to be considered a cardiac surgery case, the patient's most responsible diagnosis must be cardiac surgery. The patient may have a second or third diagnosis as well. The cardiac surgery case could include a number of individual procedures that were carried out during the patient's stay.

Consistent with the HSRC, the SPSRC reviewed data with the same parameters in order to build upon the HSRC's work, confirm trending and make recommendations.

Notable differences from the HSRC's approach included a review of data over several years, while the HSRC referenced a single year of data (1995/96). Also, the SPSRC reviewed data from two additional age groups, namely the 15 to 18 years age group and the neonate group as well as data for same day surgery. These were not reviewed by the HSRC.

The tables provided in this report use 1995/96 as a starting point for review. Where the HSRC data were not available for the additional age groups reviewed by the SPSRC, 1996/97 is the starting point for the review.

The reader will note that ranges of data, rather than discrete numbers are used in some of the table and chart presentations. This is in order to comply with the "identity component" in the definition of "personal information", in Section 2 of the Freedom of Information and Protection of Personal Information Act. The Ministry of Health and Long-Term Care Corporate Policy Directive entitled, "Security of Health and Associated Personal Information, Small Cell Count and Residual Disclosure", precludes disclosure of "small cell counts" which is generally regarded as values less than five (5).

Note: The SPSRC was provided with additional reports of cardiac surgery activity collected through the cardiac database maintained by The Hospital for Sick Children. These reports used different reporting parameters by tracking cardiac procedures rather than the national and provincial reporting standard of CMGs. The SPSRC agreed that regardless of the data source and the specific parameters placed on data retrieval, the overall numbers confirm an overall decline in the tertiary pediatric cardiac surgical volumes.

(ii) Provincial Context

Tertiary Pediatric (In-Patient) Surgery

Data were extracted for the pediatric age groups consisting of neonates (i.e., newborns from 0 to 28 days), 0 to 4 years, 5 to 9 years and 10 to 14 years. This data set consists of all tertiary pediatric surgeries including tertiary pediatric cardiac surgery.

Tertiary pediatric services occur in a select number of hospitals province-wide including academic health science centres (AHSCs) and larger community hospitals with more specialized concentrations of services. Since 1995/96, the total annual volume of all specialized surgical procedures in the 0 to 14 age group has declined from 6,286 to 5,287 or by 15.9%. Over the same time period, the AHSCs have accounted for an increasing proportion of these procedures. (Please see Figure 1 below and Appendix 5).

Between 1996 and 2000, the 0 to 14 population in Ontario remained relatively constant, in contrast to the total population, which grew by almost 5%. The provincial population growth rate is expected to continue to outpace the growth rate in the 0 to 14 age group, which, in fact, will experience a negative growth rate. Between 1999 and 2010, the 0 to 14 population in Ontario is expected to decline by 4.8%, from 2,271,929 to 2,163,736. By contrast, the total provincial population is expected to grow by 13.5% from 11,513,811 to 13,065,586 over the same period.

Figure 1
Percentage of Provincial Tertiary Pediatric Surgical Procedures by age group undertaken by the Academic Health Science Centres (AHSC)

All AHSCs	Age 0-4	Age 5-9	Age 10-14	Total 0-14
1995/96	83.6%	75.9%	79.6%	80.0%
2000/01	94.0%	89.8%	83.9%	90.6%

Tertiary Pediatric Cardiac (In-Patient) Surgery

Tertiary pediatric cardiac surgery cases account for approximately 12% of the total tertiary pediatric surgical cases. This percentage has remained relatively constant from 1995/96 (11.6%) to 2000/01 (12.1%).

Consistent with a decline in overall tertiary pediatric in-patient surgical volumes, tertiary pediatric cardiac surgery has declined from 727 total cases in 1995/96 to 638 total cases in 2000/01 or by 12.2% for the 0 to 14 age group (Please see Figure 2 below).

Changes in medical practice, in large part, appear to account for a shift in the percentage of tertiary cardiac cases by the age groups. Looking at the age group 0 to 14 years (excluding neonates) as was the HSRC's focus, in 1995/96, the 0-4 age group accounted for 41.5% of the total tertiary cardiac surgical cases. In 2000/01, the 0 to 4 age group represented 69.0% of the total cases. The data are consistent with the recent change in practice in which multiple interventions are now completed during one operation rather than as a series of separate procedures over time. As well, these procedures are being done in younger children. This likely obviates the need for repeat surgery at later stages in life.

Figure 2
Provincial Tertiary Cardiac Surgery In-Patient Volumes by Age Group

Age Group (years)	1995/96		2000/01	
	<i>cases</i>	<i>%</i>	<i>cases</i>	<i>%</i>
0 - 4	302	41.5	440	69.0
5 - 9	253	34.8	89	13.9
10 - 14	172	23.7	109	17.1
Total (0 - 14)	727	100.0	638	100.0

Cardiac Same Day Surgery

The SPSRC physician representatives noted the increasing trend toward the use of interventional catheterization in place of cardiac surgery procedures. To review this trend, Same Day Surgery (SDS) volumes from 1996/97 to 2000/01 were collected from the CIHI files and provided to the SPSRC. This data set is based upon CCSP procedures 47.00 to 49.99, which for SDS volumes, is grouped into day patient groupings (DPGs). As the algorithm used to define tertiary cases is based on CMGs, it is not possible to isolate the SDS procedures that are specifically tertiary in nature. This limitation does not allow trends to be accurately tracked, but may explain the higher than expected number of non-AHSC hospitals that have reported SDS cardiac procedures.

Provincially, from 1996/97 to 2000/01, same day surgical cardiac cases increased by 16.1% in AHSCs. The increase in SDS cases may in part account for the decline in in-patient tertiary cardiac cases. However due to the data limitations as stated above, it is not possible to confirm the actual direct impact of SDS cases on inpatient tertiary cardiac surgery. From 1996/97 to 2000/01, The Hospital for Sick Children SDS cases increased by 61.8%; London increased by 30.6% and CHEO's SDS volumes decreased by 37.1%.

Figure 3

Same Day Cardiac Surgery Cases for the 0 to 18 Age Group (excl. neonates)

Cardiac Same Day Surgery – 0 - 14 yrs.	London	Ottawa CHEO	Toronto HSC	Hamilton	Kingston	All Other Hospitals	Total
1996/97	36	70	76	<5	0	37	220-223
2000/01	53	47	126	9	0	37	259

The London volumes include London Health Sciences Centre and St. Joseph's, London.

Hamilton volumes include the McMaster site of the Hamilton Health Science Centre.

Kingston volumes include Kingston General Hospital and Kingston Hotel Dieu. The pediatric program has since transferred to KGH.

(iii) Site by Site Volumes of Cardiac Tertiary Pediatric In-Patient Surgery

The SPSRC undertook a detailed review of the volumes by site, reviewing compiled data from 1996/97 to 2000/01 to determine what has changed since the time of the HSRC review. As noted previously, the HSRC did not undertake detailed reviews of the neonate or the 15 to 18 age groups.

There has been an overall decline of 12.2% in volumes in the 0 to 14 age group between 1995/96 and 2000/01, however, the degree of change has varied by AHSC.

Of the five pediatric academic health science centres data reviewed, only LHSC, CHEO and The Hospital for Sick Children provide any significant volumes and are the only centres that report neonatal cardiac surgery.

Although the centres in Hamilton or Kingston did not report any tertiary pediatric cardiac surgical activity at the time of the HSRC report, they have since reported very low volumes for the 0 to 14 age group (excluding neonates), in the period 1996/97 to 2000/01.

The following tables below indicate the percentage of total tertiary cardiac surgery volumes by age group that were undertaken by the individual sites over the last six years.

Figure 4

Percentage of Total Provincial Tertiary Pediatric Cardiac Surgery Cases by Centre

Neonates	London	Ottawa CHEO	Toronto HSC	All Other
1996/97	15.8%	26.3%	57.9%	0%
2000/01	5.0%	5.0%	90.0%	0%

0 to 14 yrs.	London	Ottawa CHEO	Toronto HSC	All Other
1995/96	8.4%	13.5%	75.2%	2.9%
2000/01	13.0%	14.1%	69.1%	3.8%

Figure 4 (con't)

15 to 18 yrs.	London	Ottawa CHEO	Toronto HSC	All Other
1996/97	13.7%	9.4%	35.0%	41.9%
2000/01	11.4%	6.7%	34.2%	47.7%

Note:

"All Other" includes Hamilton and Kingston centres.

The HSRC considered cardiac surgery volumes for pump cases as a gauge of the complexity of the tertiary pediatric surgical cases. The Hospital for Sick Children continues to provide the highest volumes for pump surgery with 72.3% of cases requiring pumps in 2000/01 for the 0 to 14 age group.

Figure 5**Percentage of Total 0 to 14 cases involving a Pump by Centre**

Procedures with Pump 0 to 14 yrs	London	Ottawa CHEO	Toronto HSC	Hamilton	Kingston	Other
1995/96	5.3%	13.1%	81.4%	N/A	N/A	0.2%
2000/01	14.5%	12.9%	72.3%	N/A	N/A	0.3%

The Hospital for Sick Children, Toronto

The Hospital for Sick Children experienced the greatest decline in overall age 0 to 14 volumes (decrease of 19.4 %), however, the hospital continues to be the significant provider in both volume and complexity of cases. HSC has particularly played a predominant role in neonatal tertiary cardiac surgery. In 1996/97 HSC was responsible for approximately 58% of all neonatal tertiary cardiac surgery. In 2000/01, it provided 90% of all neonatal cardiac surgery as the province's AHSCs have transferred most of these cases to HSC. Over the six-year period, there was an average of 509 tertiary pediatric cardiac surgery cases annually at HSC.

Figure 6**Tertiary Cardiac Surgery Cases In-Patient – The Hospital for Sick Children**

Age (years)	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01
0-4	233	385	391	314	317	305
5-9	194	88	101	85	85	68
10-14	120	70	92	79	58	68
Total 0-14	547	543	584	478	460	441
15 to 18	N/A	41	34	48	46	51
Neonate	N/A	11	9	7	11	18
Total 0-18	N/A	595	627	533	517	510

Children's Hospital of Eastern Ontario, Ottawa

CHEO has experienced an 8.2% reduction in tertiary pediatric cardiac surgery cases between 1995/96 and 2000/01 for the age group 0 to 14 years (excluding neonate). Based on CIHI data, CHEO experienced an average annual volume of 104 cases over the six years. When neonates and 15 to 18 age groups are included, CHEO has averaged 121 annual cases over the six years.

CHEO experiences the highest use of the tertiary cardiac service by non-Ontario residents. CHEO has indicated that Newfoundland has accounted for a number of these cases, as have residents of Quebec. Out-of-Province cases have constituted from 22 to 35% of the total CHEO tertiary cardiac surgery cases in a 5-year period. CHEO is a facility that is designated under the French Languages Services Act and provides service in both official languages. The ability to provide services in French was noted by the HSRC in their report.

The HSRC expressed concern over the low volumes experienced by CHEO and recommended that volumes be monitored over an 18-month period to see if suggested annual minimum volumes of 200 were achieved. Since the HSRC review, the CHEO in-patient volumes have further declined to 90 in-patient cases for the 0 to 14 population. With the inclusion of neonates and 15 to 18 year-olds, volumes of tertiary pediatric cardiac surgery remain significantly below the HSRC recommended annual minimum of 200 tertiary cardiac surgery cases (101-104 cases in 2000/01) based on CIHI data.

Figure 7

Tertiary Cardiac Surgery Cases In-Patient--CHEO

Age (years)	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01
0-4	45	75	83	67	65	65
5-9	32	25	14	22	20	9
10-14	21	16	22	11	18	16
Total 0-14	98	116	119	100	103	90
15-18	N/A	11	16	16	9	10
Neonate	N/A	5	6	<5	<5	<5
Total 0-18	N/A	132	141	117-120	113-116	101-104

London Health Sciences Centre, London

Over the period 1995/96 to 2000/01, tertiary pediatric cardiac surgery cases have increased by 36.1% from 61 to 83 (0 to 14), however, volumes remained significantly below the HSRC's recommended annual minimum of 200 cases. When neonates and ages 15-18 are included, volumes were 101 to 104 in 2000/01. London experienced average annual volumes of 75 cases for the 0 to 14-year age group. If neonates and the 15 to 18 age groups are included, the average annual volumes were 95 cases for the six years.

In October 2001, the LHSC Board supported closure of the pediatric cardiac surgical program. The volumes have since transferred to The Hospital for Sick Children. Prior to the closure, the hospital halted two specific surgical procedures, namely, the arterial switch and Norwood procedures.

Figure 8**Tertiary Cardiac Surgery Cases In-Patient -- London**

London Volumes	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01
0-4	21	45	43	65	62	61
5-9	22	21	9	13	9	9
10-14	18	6	12	10	10	13
Total 0-14	61	72	64	88	81	83
15-18	N/A	16	9	11	15	17
Neonate	N/A	<5	7	<5	<5	<5
Total 0-18	N/A	89-92	80	100-103	97-100	101-104

(iv) Key Observations and Trends

1. The incidence of congenital heart disease (CHD) is expected to remain the same over time. There does not appear to have been a significant increase in the incidence of CHD over the last 20-30 years. (Hoffman in Pediatric Cardiology, Volume 16, Number 3, 1995)
2. The total number of surgeries is declining given that multiple interventions are now completed during one operation.
3. The pediatric population aged 0 to 14 is expected to decline by 4.8 % between 1999 and 2010.
4. Over the period 1995/96 to 2000/01, provincial tertiary pediatric surgical cases (all tertiary pediatric surgeries including cardiac) have decreased by 15.9% since the HSRC undertook its review. (Appendix 5)
5. Tertiary pediatric cardiac surgical cases in the province decreased by 12.2% since the HSRC review, that is, from 1995/96 to 2000/01 (Figure 2). Including neonates and age 15 to 18 cases, there has been a 9.6% decrease (reduction from 898 to 807) in tertiary pediatric cardiac surgery cases between 1996/97 and 2000/01.
6. Between 1995/96 and 2000/01, CHEO conducted an annual average of 104 tertiary pediatric cardiac surgical procedures on the 0-14 age group. CHEO tertiary pediatric cardiac surgery cases (0 to 14 age group) range from a high of 119 in 1997/98 to a low of 90 in 2000/01. (Figure 7)
7. Including the neonate and age 15-18 cases, CHEO experienced an annual average of 121 tertiary pediatric cardiac surgical procedures between 1996/97 and 2000/01. If activity in other Ottawa hospitals (e.g. Ottawa Heart Institute and The Ottawa Hospital sites) are included, the average annual tertiary pediatric cardiac surgery cases in Ottawa is 132 for the same period. (Figure 7)

8. CHEO has a high utilization by non-Ontario residents ranging from a low of 21.8% of total tertiary pediatric cardiac surgery cases (age 0-14) volumes to a high of 35% in 1998/99. Utilization of The Hospital for Sick Children by non-Ontario residents has declined from a high of 10.3% of total tertiary pediatric cardiac surgical cases at the hospital in 1996/97, to 4.8% in 2000/01.
9. Between 1995/96 and 2000/01 London conducted an annual average of 75 tertiary pediatric cardiac surgical procedures on the 0-14 age group. London tertiary pediatric cardiac surgery cases range from a high of 88 (0 to 14 age group) in 1998/99 to a low of 61 in 1995/96. (Figure 8)
10. Including the neonate and age 15-18 cases, London hospitals experienced an annual average of 95 cardiac surgical procedures between 1996/97 and 2000/01. (Figure 8)
11. The Hospital for Sick Children performed a high of 584 tertiary pediatric cardiac surgery cases (ages 0 to 14) in 1997/98 but has decreased to 441 cases in 2000/01. Of all the centres, The Hospital for Sick Children experienced the greatest decline in tertiary pediatric cardiac surgical volumes: 19.3% between 1995/96 and 2000/01. (Figure 6)
12. Even with the decline in overall tertiary pediatric cardiac surgery cases there does not appear to have been any significant shift in services from one site to another.
13. The HSRC recommendations to consolidate tertiary pediatric cardiac surgery were based on information from 1995/96, when volumes were higher than current levels. There does not appear to be any new statistical evidence to support a change to the HSRC recommendations. Overall, tertiary pediatric cardiac surgery cases have declined since 1995/96. This supports a single provincial provider of tertiary pediatric cardiac surgery as was suggested in the HSRC Report.
14. CHEO tertiary pediatric cardiac surgical in-patient cases have decreased since the time of the HSRC review when the HSRC recommended that CHEO be monitored over an 18 month period to determine if the goal of 200 cases annually could be met.
15. The decision of the LHSC Board to discontinue tertiary pediatric cardiac surgery is consistent with national and international research and trends and supported by a province-wide review of the number of children requiring cardiac surgery.

(v) Key Considerations

The SPSRC raised a number of issues for consideration in relation to the future configuration and provision of tertiary pediatric cardiac surgery services. These were first articulated in the SPSRC's initial meeting and expanded upon throughout the duration of the meetings. Members identified a number of criteria in developing recommendations for tertiary pediatric cardiac surgery.

These issues and criteria are summarized below. The criteria are listed in Appendix 3.

Changes in Pediatric Cardiac Surgery Practice

One noticeable trend since the time of the HSRC's work, was that the volumes of inpatient tertiary pediatric surgery overall, as well as the volumes of inpatient tertiary pediatric cardiac surgery, were decreasing.

The SPSRC suggested various explanations for this trend. In the case of cardiac surgery, it felt the most likely reason was that the care of children with congenital heart disease has changed dramatically, as the actual incidence of congenital heart anomalies has remained constant in the population. For example, the vast majority of children born with an atrial-septal defect (a hole between the top chambers of the heart) can now have their condition corrected in the cardiac catheterization laboratory. The hole is closed, non-surgically by the insertion of a device, through a catheter. There is a low complication rate and an excellent success rate associated with this approach and it allows the child to recover faster compared to surgical approaches.

With the ability to intervene at earlier ages, improvement in technique and advancing technology, many other congenital heart defects no longer require multiple operations. The technology may allow for several procedures to occur during one operation. This would help explain the trend noted above.

This phenomenon will continue as the overall practice of medicine responds to new research and changes in technologies and therapies shape the future.

In relation to this trend, the SPSRC noted that important criteria in the design for any cardiac program would include both *program stability* over a longer time period and an *ability to recognize and adapt to changes in practice*.

Clinical research indicating that outcomes are related to volumes

Various researchers have clearly established the direct linkage between the number of procedures done and successful outcomes.

The SPSRC noted that the statement 'practice makes perfect' extends to both individuals and programs. In fact, an area of strong consensus for the SPSRC was that thresholds (minimum volumes of procedures, or specific activities) to maintain clinical proficiency/competency were as important for the *entire team* supporting patient care (physicians, nurses, perfusionists, infection control specialists, nutritionists, respiratory therapists, other allied health

professionals) as for the *individual physicians* themselves. Likewise, the requirement for 'critical mass' extends to both a critical mass of patients for the team to maintain its skills and expertise and a critical mass of human resources to support the multiple facets of a program.

The SPSRC discussed measures to safeguard against the potential of putting patients in a vulnerable position if there was a dependency on a sole program or a sole specialist and an unforeseen departure or catastrophic event occur. These measures included sharing knowledge and experience amongst centres of expertise, and that in the area of tertiary pediatric cardiac surgery, a minimum of two pediatric cardiac surgeons were required at a centre to ensure necessary coverage throughout the year.

The SPSRC also discussed the importance of having back-up services available in other centres in the event of a temporary loss of capacity in a single centre. For some complex procedures, it realized it would have to seek this support outside Ontario.

Best Interest of Children

The SPSRC frequently reinforced that recommendations be made in 'best interest of the patient'-- in this case, children requiring highly specialized tertiary pediatric cardiac surgery. The components of 'best interest' to which the SPSRC gave consideration included mortality, morbidity and timely access to care. The SPSRC recognized that these criteria could impact each other. The need to travel may be increased if services are consolidated; whereas, the lowest mortality rates and therefore, best outcomes will be ensured with service consolidation. The SPSRC recognized that many people associate services 'close to home' as being in the best interest of children and may not be aware of mortality rates that can vary. The SPSRC also discussed necessary safeguards to maintain timely access and minimize morbidity, should there be further program consolidation.

Interdependencies among Pediatric Cardiac Surgery, Pediatric Cardiology and Other Pediatric Programs

It became apparent early on in the discussions, that there were tremendous interdependencies among tertiary pediatric cardiac surgery, pediatric cardiology and other pediatric programs. These interdependencies can be characterized as the myriad of relationships that exist amongst departments in a hospital that are required to support a program, and the relationships between the hospitals and universities whose academic programs educate and train future clinical professionals.

Changes to one component would have direct and indirect effects on other components. These changes were already being experienced in London, where the impact of redistributing an additional 100 tertiary pediatric cardiac surgery cases from London's referral area was in process. There is a direct impact on the centre(s) that are receiving the additional cases in that a centre with an increased number of cardiac surgical cases will also be required to increase the proportion of critical care resources dedicated to this population. There is a potential indirect effect on all the pediatric AHSCs if, for example, the centre(s) with the additional cases were required to refocus their own activities (e.g., by reducing the number of other types of cases, to accommodate the change). The centre(s) with the additional cardiac cases may need to transfer out other cases requiring critical care if in-centre expansion is not sought or supported.

This series of complex interrelationships and interdependencies requires all AHSCs to collaboratively plan together. The SPSRC felt that each AHSC needed a viable pediatric general cardiology program to provide aspects of pre- and post-surgical care, regardless of the number of tertiary pediatric cardiac surgical programs.

The HSRC noted that the provisions in the Royal College of Physicians and Surgeons (Ontario) guidelines for critical care training programs does not require all elements of the training to be completed through one residency program. Formal arrangements between accredited residency programs can accommodate situations where residents may receive their training in more than one program.

The SPSRC discussed potential impacts of any changes of tertiary pediatric cardiac surgery program location on pediatric residency training in terms of these academic interdependencies. It saw the establishment of alternative funding programs (AFPs) as vital to the delivery of pediatric cardiac care in the province. The SPSRC also noted the importance of clinical coherence, where there may be relative benefits of locating programs in conjunction with, or close to, related programs.

Accessibility

Ontario has a legal commitment to provide services in both official languages and has designated a number of agencies and programs in this regard. Both CHEO and HSC are designated to provide services under the French Language Services Act.

Other important aspects of accessibility are the geographic and demographic realities of the province. Earlier discussions about population statistics show that the 0 to 14 age group, expressed as a percentage of the total population, is decreasing, with the trend expected to continue.

The SPSRC noted that whatever the future program configuration, there were out of pocket costs borne by family members who are required to travel with their children and stay with them during their course of treatment. Centralization will like result in additional costs for some families. The SPSRC recognized that while some families are eligible to have transportation costs defrayed (e.g., northern communities), this issue would require further review and that there might be major implications for existing ministry policy.

Program Cost

The SPSRC did not undertake a detail costing of programs or cost implications of these programs. Rather, it reflected on the cost to the system of having duplicate specialized programs across the province, in lieu of other program investments; the feasibility of maintaining or implementing any new program or role and the existing capacity amongst the centres to carry out the roles prescribed.

This last point was particularly noteworthy for the SPSRC in its discussions regarding the number of surgical programs and the siting of the program. The SPSRC did not consider it feasible to invest in developing/opening a new site if there was capacity in the current configuration of programs.

(vi) Tertiary Pediatric Cardiac Surgery Recommendations

The SPSRC put forward the following recommendations with respect to the provision of tertiary pediatric cardiac surgery services in the province. The implementation of these recommendations holds patient safety and quality of care as the primary considerations that determine the model for the program. The recommendations also promote future networking in order to support a provincial program and system of care in pediatric cardiac medicine as a template for other highly specialized pediatric programs.

Recommendation 1

To ensure best outcomes, a coordinated system of tertiary pediatric cardiac services is required in the province and includes both surgical and medical services. The five academic centres should build on the experience of the SPSRC and commit to closer, collaborative relationships to effect this change and ensure access to specialized care. Please refer to Section VI, subsection (vii) and Section VIII, subsection (iii) for elaboration on this model.

Recommendation 2

Tertiary pediatric cardiac surgery should be centralized on one site with a targeted implementation date of April 2003. The recommended site is The Hospital for Sick Children.

The recommendation to consolidate tertiary pediatric cardiac surgery on one site extends to all Ontario hospitals now performing tertiary pediatric cardiac surgery services, except in children requiring surgical ligation of a patent ductus arteriosus. In these latter patients, ligation may occur in an Ontario academic centre with neonatal and surgical expertise.

Recommendation 3

Given that current medical practice recommends on-site surgical back-up for interventional catheterization procedures, pediatric cardiology using these methods, including immediate post-operative intensive care, should also be centralized at the same site, unless otherwise agreed to by members of the pediatric cardiac network (a medical forum proposed by Chairs/Chiefs not yet established).

A number of factors have influenced the SPSRC's recommendation of a one-site model and the goal of a specialized pediatric cardiac program in Ontario. These include but were not limited to the following:

- Patient safety and quality of care of the patient as the primary considerations
- Review of current and historical volumes at CHEO, LHSC, HSC indicates a continued decline in tertiary pediatric cardiac surgery volumes

- Literature review of national and international trends support consolidation
- Research provides evidence of improved patient outcomes in centres with volumes sufficient to maintain expertise

The HSRC Report recommended that volumes at CHEO be monitored over an 18-month period to determine if the CHEO program would meet a minimum volume of 200 cases per year. In the period between 1996/97 and 2000/01, volumes at CHEO have continued to decline. Continued declines will have a possible negative impact on patient care and will reduce the capability of the tertiary pediatric cardiac surgical and nursing teams to maintain adequate levels of expertise.

LHSC discontinued its tertiary pediatric cardiac surgical program in November 2001 and volumes were transferred to The Hospital for Sick Children.

Recommendation 4

The five AHSCs will collaborate with the Ministry of Health and Long-Term Care to make further recommendations on the provision of supports for families travelling greater distances for tertiary pediatric cardiac surgery and include the possibility of non-governmental partners as funding supports.

The SPSRC recognizes that the impact on some families will be greater as a result of consolidating tertiary pediatric cardiac surgery in terms of transportation and need for out-of-town accommodation. A system of supports including short-term accommodation should be made available to the families. It was noted that access to facilities such as the Ronald McDonald House is very limited. Developing accommodation plans is seen as a priority to help facilitate travel and accommodation for potentially 200 families who will be travelling greater distances to access care in Toronto.

Recommendation 5

To support the tertiary pediatric cardiac surgery program transfer and consolidation of these services on one site, a regional model for pediatric intensive care, including pre-operative and post-operative care must be developed.

In recognition of the need to maintain a critical mass of pediatric patients in Ontario's critical care units, the intensive care medical directors in the five academic health science centres are encouraged to develop strategies to improve access to critical care. The development of this regional model should also address the need to enhance inter-hospital pediatric critical care transport.

Recommendation 6

Pediatric cardiac specialists in a tertiary pediatric setting should undertake tertiary pediatric cardiac surgery involving neonates and the 0 to 14 age groups.

Data reviewed by the SPSRC indicate that some children aged 15 to 18 may be treated in an adult setting and that some of these settings are not academic health science centres. While the preference is to treat children who have not reached puberty in a pediatric setting, the SPSRC recognized patients aged 15 to 18 years may be treated in specialized, adult cardiac surgery programs on a case by case basis.

Recommendation 7

The single site must be capable of providing services in both Official Languages.

Consolidation of all tertiary pediatric cardiac surgery services on one site requires that patients and families are ensured access to services in both Official Languages through formal designation of the cardiac program under the French Language Services Act. As part of the consolidation, the ministry will work with The Hospital for Sick Children to establish target dates for early development and implementation of a plan that will achieve formal designation of the cardiac program.

(vii) Strategies to Improve the Networking of Pediatric Cardiology and Tertiary Pediatric Cardiac Surgery in Ontario

During this review, the Chairs/Chiefs of Pediatrics recommended a number of strategies to maintain a viable and vigorous pediatric cardiology program at each of the five academic health science centres (AHSCs). These strategies include:

Patient Care

- Improved access to The Hospital for Sick Children's cardiac surgery and cardiology expertise. This could include improved telemedicine linkages between the AHSCs and major centres in Thunder Bay, Sudbury and Windsor.
- Maintaining a pediatric cardiology program at each of the 5 AHSC with hospitals and universities developing career pathways for pediatric cardiologists at non-surgical AHSCs.

Education

- Augmenting the continuing education of pediatric cardiologists by expanding the existing HSC-McMaster model to the other AHSCs.
 - Cardiologists at Hamilton, CHEO, Kingston and London AHSCs would be on site at The Hospital for Sick Children for up to 28 days each year or pre-arranged intervals.
 - Cardiologists from The Hospital for Sick Children would be on site at Hamilton, CHEO, Kingston and London at prearranged intervals to both interact with, and provide continuing medical education to their colleagues
- Work with the Royal College of Physicians and Surgeons (Canada) and training program directors to provide pediatric cardiology trainees with educational experience suitable for long-term careers in the non-surgical pediatric cardiac centres.

Research

- Develop an Ontario-wide pediatric research network that could focus on "aftercare" and long term outcomes, thereby enabling any of the AHSCs to be the lead institution for the research project. This would capitalize on HSC-based North American and Canadian databases and expertise at McMaster on the long-term outcomes of serious pediatric diseases.
- Develop Research Training Programs for pediatric cardiology trainees by building upon existing clinician-scientist-training programs at the HSC and the submission to the Canadian Institute of Health Research (CIHR) for a Canada-wide training program for clinician

scientists.

The Chairs/Chiefs also regarded issues such as improvements in coordination, the provision of transport services to/from cardiac surgical centres and the establishment of alternative funding plans in each of the AHSCs as essential to the success of any network. Please see Section VIII for details of a proposed Specialized Pediatric Coordinating Council (SPCC).

SECTION VII: PEDIATRIC TRANSPLANTATION PROGRAMS

The review of pediatric transplantation programs was limited to examining the volumes for three types of solid organ transplantations, as per the HSRC review. This included the review of kidney, liver and heart transplantation volumes at the AHSC sites.

FOIPPA reporting restrictions related to small cell counts, where volumes are less than five and there is a risk of residual disclosure, limits the presentation of much of the individual hospital data in this section of the report.

(i) Provincial Context

Compared to absolute volumes of tertiary pediatric surgical cases, there are relatively few solid organ transplantations that occur in the pediatric population in Ontario. The SPSRC reviewed the data available, however, it recognized that the quality of evidence, in terms of relatively small numbers, or the large impact of small changes in the volumes, did not result in as compelling recommendations about siting of programs as was the case with tertiary pediatric cardiac surgery.

Kidney Transplantation

Between 1995/96 and 2000/01, the total number of pediatric kidney transplants in Ontario, reported through CIHI, has declined from 16 to 13 for the 0 to 14 age group. This represents a 19% decline in total pediatric cases. Historically, The Hospital for Sick Children has been the only significant provider of kidney transplant services for the 0 to 14 population providing 90% to 100% of all kidney transplants annually.

Kidney transplants in the 15 to 18 year age group have increased from 5 in 1995/96 to 14 in 2000/01. The Hospital for Sick Children performed 66% of the kidney transplants in the 15 to 18 year age group in 2000/01.

In 2000/01, HSC conducted 12 of 13 kidney transplants in the province for the 0 to 14 population. The 13th kidney transplant was conducted in a non-pediatric hospital setting. HSC conducted 10 out of a provincial total of 14 kidney transplants for the 15 to 18 age group.

Liver Transplantation

Pediatric liver transplants, as reported through CIHI, are provided only at the London Health Sciences Centre and The Hospital for Sick Children. The Hospital for Sick Children is the only centre historically providing liver transplant services to neonates.

In 1995/96, a total of 15 pediatric liver transplants were performed in Ontario for the 0 to 14 age group. In 2000/01, the same total number of transplants (i.e., 15) was reported to CIHI by the two hospitals.

In 1995/96, London provided 27% of the liver transplant service for the 0 to 14 age group, increasing to 40% in 2000/01. London has over time, provided a greater share of the provincial liver transplant volumes.

In 1995/96, pediatric cases accounted for 6.3% of London's total liver transplant cases. In 2000/01, pediatric cases accounted for 10% of its total liver transplant cases.

Heart Transplantation

Pediatric heart transplantation currently only occurs at The Hospital for Sick Children. In 2000/01, 19 heart transplants (0 to 18 years) occurred at HSC.

(ii) Pediatric Transplantation Program Recommendations

In making its recommendations for pediatric transplantation programs, the SPSRC focused on identifying the site(s) where solid organ insertion and immediate pre- and post-operative care would occur. It is recognized that some centres (e.g., CHEO with respect to pediatric nephrology) would continue their role looking after patients both pre- and post-surgery.

Recommendation 1

The Hospital for Sick Children should continue to be the sole provider of heart transplant services for the pediatric population.

Recommendation 2

The Hospital for Sick Children should continue its role as the sole provider of kidney transplantation services for children aged 0 to 14 years, recognizing that London provides kidney transplantation to the 15-18 age group.

Recommendation 3

The SPSRC does not recommend a change to the delivery of liver transplantation services at the HSC and LHSC at this time. Program consolidation however, may be a future consideration for review by the proposed Specialized Pediatric Coordinating Council (SPCC) when it is established.

Recommendation 4

All other pediatric solid organ transplantations (e.g., lung, small bowel) should continue to be solely provided at The Hospital for Sick Children. The referring centres will continue to offer pre- and post-surgical transplantation care in a coordinated manner.

Recommendation 5

The proposed SPCC should give future consideration for a more in-depth review of provincial transplantation services with respect to considerations of quality of care, best outcomes and critical mass and pre- and post-surgical care. This review should extend to all hospitals offering pediatric transplant services.

SECTION VIII: FUTURE OPPORTUNITIES for COORDINATION OR CONSOLIDATION OF SPECIALIZED PEDIATRIC SERVICES

Part of the SPSRC's mandate included outlining programs requiring future examination for a potential to coordinate or consolidate through a network of specialized pediatric services. This task is rooted in the HSRC Report and its recommendation that a pediatric coordinating group be established with major secondary, tertiary and quaternary pediatric hospital providers.

(i) Guiding Principles

The SPSRC first developed a series of principles to guide the ongoing collaboration efforts. These included providing care driven by quality/best possible outcomes, sited locally where feasible, benefiting from national and provincial networks and ensuring that each of the five pediatric AHSCs:

- provides a broad spectrum of acute specialized services
- has an alternate funding plan for its physicians
- has shared expertise
- is enabled, building on its strengths, to identify specific program areas for specialized pediatric expertise and services.

The SPSRC also agreed that physicians associated with AHSCs should recognize the importance of a multidisciplinary team and that physician sub-specialist training programs must be designed to allow for a spectrum of clinical experiences that are applicable to all pediatric AHSCs.

(ii) Potential opportunities to be explored

Through the course of the SPSRC's deliberations a number of surgical and medical programs were identified as potential opportunities for future discussion. Opportunities for program rationalization, regionalization and/or coordination in medical sub-specialties were considered fewer than in surgical sub-specialties, given the need for continuity of care at each of the ACHCs. The SPSRC also recognized there were other forums where related discussions may be occurring, e.g., Ontario Trillium Gift of Life Network (for organ and tissue donation and transplantation) and Provincial Burns Care Task Force (for adult and pediatric burn care).

Potential opportunities include:

Tertiary pediatric surgery

- Solid organ transplantation
- Facio-maxillary reconstruction
- Vault cranio-facial surgery
- Complex urology
- Complex orthopedics
- Complex general surgical procedures (e.g., Kasai procedure for biliary atresia)
- Neurosurgery
- Burns
- Trauma

Pediatric Medicine

- Mechanism for sharing of sub-specialty expertise across province
- Pediatric transport
- Critical care
- Poison information

The SPSRC also agreed that facilitation of best practices needed to be encouraged and that there be deliberations regarding the links between AHSCs and the Home Care supports and services available. Although Home Care is not a specialized program per se, the SPSRC noted that community-based specialized pediatric expertise (especially nursing) is often lacking and impacts the discharge process and transition to home for children requiring specialized long-term care.

(iii) Proposed Process for ongoing collaboration

Specialized Pediatric Coordinating Council (SPCC)

Three optional approaches were identified to bring some structure to ongoing collaboration and exploration of further opportunities for coordination of hospital-based specialized pediatric services that are low in volume and highly specialized. The use of one approach does not preclude an alternate approach being used as well. The options include:

- continuation of the current SPSRC deliberations
- use of the Provincial Pediatric Chairs/Chiefs forum and the establishment of an Administrative Leaders group to allow for discussions
- establishing a mechanism which allows for wider participation by those who are impacted by potential consolidation and coordination.

Outlined below is an elaboration of the third approach and recommends the creation of a Specialized Pediatric Coordinating Council (SPCC) for hospital-based specialized pediatric services.

The SPCC would be advisory to the Ministry of Health and Long-Term Care and would provide an ongoing focus on the provision of highly specialized, tertiary and quaternary services for children.

Focus

The SPSRC identified several program areas where information and discussion was required before any recommendations could be made for further coordination and consolidation.

The SPCC would consider each of the programs identified by the SPSRC and make recommendations on the future configuration of each of the programs.

In making its recommendations, the SPCC would consider mechanisms/initiatives for province-wide implementation/collaboration among the centres to ensure:

- the development of provincial systems are linked to regional initiatives (e.g., child health networks) and that they support each other
- access to specialized children's services is maintained
- programs and services are of the highest quality possible
- consistent best practices are implemented and outcomes measures evaluated for children with regard to tertiary/quaternary programs.

These activities could include, but not be limited to the following:

- Single registry and single system of referral and placement for specialized/tertiary cases
- Linkages with referral centres
- Monitoring and managing patients on a single, centralized waiting list
- Monitoring outcomes of diagnostic and therapeutic interventions
- Referral of out-of-province elective admissions to the most appropriate hospital
- Formal agreements between pediatric academic health sciences centres to allow completion of residency requirements/training in more than one accredited centre
- Adoption of provincial clinical guidelines and treatment protocols
- Strategies on shared human resource issues, including recruitment and retention strategies for medical staff and other health professionals
- Development of health human resource ratios for pediatric subspecialties required for fulfillment of teaching, research and patient care needs

Membership

The SPSRC suggested that membership initially include the five pediatric AHSCs (both administrative and clinical leaders) with future consideration to include other centres that would be impacted by consolidation/coordination of specialized pediatric services. The one exception would be that a representative from Northern Ontario be included (e.g., either from Thunder Bay Regional or Sudbury Regional hospitals, which have modified level III neonatal intensive care units (NICUs).

Representation from:

CHEO, Ottawa	University of Ottawa
Kingston General Hospital, Kingston	Queen's University
Hospital for Sick Children, Toronto	University of Toronto
Children's Hospital at HHS, Hamilton	McMaster University
Children's Hospital of Western Ontario at LHSC, London	University of Western Ontario
Northern Representative from either Thunder Bay Regional Hospital, Thunder Bay or Sudbury Regional Hospital, Sudbury	

Chair/Lead

- To be confirmed by the ministry

Members

Number of Members to be 14 as prescribed below:

- 5 Pediatric Academic Chairs plus physician leader from Northern Ontario
- 6 CEOs (or delegate) from the five AHSCs and Northern Ontario
- Assistant Deputy Minister, Health Care Programs
- Assistant Deputy Minister, Integrated Services for Children

The Ministries of Health and Long-Term Care and Community, Family and Children's Services would participate as non-voting members.

Frequency of Meeting

- Quarterly

Support

- Yearly budget would be established with the Ministry of Health and Long-Term Care.
- Annual review re continuation of SPCC as effective mechanism

***Note:**

Consideration that with respect to tertiary pediatric cardiac surgery, an interim working group be established through Cardiac Care Network to manage patient referrals/monitor waiting lists, until the SPCC is established, and/or program consolidation occurs.

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3. Summary of criteria for consideration in developing recommendations for tertiary pediatric cardiac surgery
4. Data Definitions
5. Graph 1 -- Tertiary Pediatric Surgical Separations in Ontario, 1996/97 to 2000/01
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8. Cardiac database maintained by HSC: HSC Cases
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APPENDIX 1

SPECIALIZED PEDIATRIC SERVICES REVIEW COMMITTEE -- MEMBERSHIP

Ms. Susan Smith
Vice President, Specialty Services
Hamilton Health Sciences Corporation

Mr. Joseph de Mora
President and Chief Executive Officer
Kingston General Hospital

Mr. Tony Dagnone
President and Chief Executive Officer
London Health Sciences Centre

Mr. Garry Cardiff
Chief Executive Officer
Children's Hospital of Eastern Ontario

Ms. Mary Jo Haddad
Vice President, Medical Services
The Hospital for Sick Children

Mr. John King
Assistant Deputy Minister, Health Care Programs
Ministry of Health and Long-Term Care

Dr. David McCutcheon
Assistant Deputy Minister, Health Services
Ministry of Health and Long-Term Care

Mr. David Stolte
Director, Health Reform Implementation Team
Ministry of Health and Long-Term Care

Mr. Peter Finkle
Regional Director, East Region
Ministry of Health and Long-Term Care

Ms. Jennifer van Sickle
Program Manager, Southwest Region
Ministry of Health and Long-Term Care

Ms. Debbie Latter
Consultant, Health Reform Implementation Team
Ministry of Health and Long-Term Care

Ms. Maureen Quigley
Facilitator
Maureen Quigley and Associates Inc.

Dr. John Watts
Academic Chair (A), Pediatrics
McMaster University

Dr. Kimberley Dow
Academic Chair, Paediatrics
Queen's University

Dr. Tim Frewen
Chair and Chief of Paediatrics
University of Western Ontario

Dr. John Joseph Reisman
Academic Chair, Pediatrics
University of Ottawa

Dr. Hugh O'Brodovich
Academic Chair, Pediatrics
University of Toronto

Ms. Gail Ure
Executive Director, Health Care Programs
Ministry of Health and Long-Term Care

Ms. Cynthia Lees
Assistant Deputy Minister
Integrated Services for Children
Ministry of Health and Long-Term Care and
Ministry of Community, Family and Children's
Services

Ms. Monita O'Connor
Program Manager, Central South Region
Ministry of Health and Long-Term Care

Ms. Marnie Weber
Regional Director, Toronto Region
Ministry of Health and Long-Term Care

Ms. Catherine Pepevnak
Hospital Consultant, Toronto Region
Ministry of Health and Long-Term Care

APPENDIX 2

MINISTER'S ADVISORY COMMITTEE SPECIALIZED PEDIATRIC SERVICES REVIEW

TERMS OF REFERENCE

I. PREAMBLE

Over the past few years, a reform of the delivery of children's services has been underway. Collaborative partnerships and local community service delivery are two of the themes adopted by the Government of Ontario for this reform. Within governmental ministries, decentralized regions for service delivery have been established as well as a new bi-ministry division between the Ministries of Health and Long-Term Care (MOHLTC) and Community, Family and Children's Services (MCFCS, formerly MCSS). The Integrated Services for Children Division's (ISCD's) role is to develop coordinated policy and program planning between MCFCS and MOHLTC, so that there is a holistic policy and program development approach to children and families.

During this same time, various parties have studied and commented on the delivery of children's services. For example, the Health Services Restructuring Commission (HSRC) commented on pediatric services in its directions and reports to local communities. Through specific HSRC directions, four child health networks have been created. Individual hospitals have also examined their corporations' roles in the provision of services to children. Throughout this, a need has been identified for strategies to ensure consistent, province-wide access to highly complex services.

On November 5, 2001, the Minister of Health and Long-Term Care announced the formation of a province-wide advisory committee to review the delivery of specialized pediatric services. This committee will examine current specialized tertiary and quaternary hospital-based programs and services and suggest ways to ensure they are viable, accessible, responsive and effective for children and their families. Specialized pediatric services under consideration include programs of the province's five pediatric academic health sciences centres.

II. PURPOSE

As per the workplan, the advisory committee will develop advice and recommendations regarding the optimum delivery of specialized pediatric services in Ontario for children up to 18 years of age. For purposes of this review, "specialized pediatric services" are considered to be hospital based, acute, tertiary or quaternary services provided by academic health sciences centres.

At a minimum, the recommendations will focus on the following areas:

- improving the coordination of specialized pediatric services in Ontario
- ensuring children in Ontario have access to a comprehensive array of specialized services
- ensuring quality outcomes and minimum volumes to maintain expertise
- identifying a collaborative process for directing patient referrals to tertiary centres
- the impact on the quality and comprehensiveness of academic programs

These recommendations will be based on the best available evidence, supplemented where appropriate by expert opinion.

III. TASKS

1. Review of the confidential report and confidential recommendations of the Health Services Restructuring Commission, *Coordinating and Consolidating Specialized Pediatric Services in Ontario (February 1999)*.
2. Review of relevant models/experiences in other jurisdictions.
3. Review of updated data related to the HSRC report.
4. Review of current specialized pediatric services at the five tertiary centres for opportunities for coordination and collaboration

IV. DELIVERABLES

1. Recommendations on the future configuration of specialized pediatric services arising from review of the HSRC report, the London Health Sciences scoping and sizing initiative, and the experiences of the provincial specialized pediatric centres.
2. Recommendations for other programs requiring examination for potential to coordinate and consolidate through a network of pediatric services.
3. Recommendations on (a) mechanism(s) for ongoing collaboration.

V. MEMBERSHIP

Chair -- Assistant Deputy Minister and Executive Director, Health Care Programs, MOHLTC

Presidents and CEOs (5) -- Pediatric Academic Health Science Centres

Pediatric Chairs (5) -- Pediatric Academic Health Science Centres

Also Attending

ADM Health Services, MOHLTC

ADM Integrated Services for Children, MOHLTC/MCFCS

Regional Directors (East, Toronto, Central South, Southwest), MOHLTC

Director, Health Reform Implementation Team, Health Care Programs, MOHLTC

Consultant, Health Reform Implementation Team, Health Care Programs, MOHLTC

Hospital Consultant, Toronto Region, Health Care Programs, MOHLTC

Facilitator

Maureen Quigley, Maureen Quigley & Associates Inc.

VI. EXTERNAL INPUT

Notwithstanding the membership, the advisory committee may seek input from independent experts and other pediatric providers. A preliminary draft of the Advisory Committee's recommendations and report will be circulated to the Ministry of Health and Long-Term Care and its feedback will be considered by the Advisory Committee before finalization.

VII. TERM

The advisory committee will complete its activities over a one to two-month period. Three facilitated meetings and two to three working meetings may be required. It is anticipated the facilitated meetings will occur by January 31, 2002. The committee's recommendations and/or report are to be completed and submitted to the Minister of Health and Long-Term Care by February 28, 2002.

VIII. ACCOUNTABILITY

The recommendations of this advisory committee will be presented to the Minister of Health and Long-Term Care.

All materials made available for use by the committee are to remain confidential until the Minister releases it publicly.

January 9, 2002

APPENDIX 3

SUMMARY OF CRITERIA

Criteria
(a) Outcome Criteria
♦ Best interest of children ♦ Mortality ♦ Morbidity ♦ Timely access to care
♦ Interdependencies ♦ Academic ♦ Clinical coherence
(b) Capacity criteria
♦ Volumes/frequency – threshold to maintain the expertise/ competency of team not just individual physicians
♦ Availability of Cardiac Surgeons – minimum of 2 required to support 24/7 care
♦ Existing capacity amongst centres
♦ Back up in event of loss of capacity in single centre
♦ Capacity in both official languages
♦ Geographic/Demographic realities of Province
♦ Cost ♦ Efficiency ♦ Financial capability of institution ♦ Cost to system of multiple programs ♦ Out of pocket costs to families
♦ Feasibility of Implementation
♦ Stability over a longer time period and ability to adapt to changes in practices

APPENDIX 4

DATA DEFINITIONS

The Specialized Pediatric Services Review Committee (SPSRC) used the Health Services Restructuring Commission's (HSRC's) approach to review the data associated with specialized pediatric services. These data are maintained through the Canadian Institute for Health Information (CIHI) and depend on the facilities themselves for the coding and submitting of data.

The HSRC tables for the fiscal year 1995/96 have been updated using the same format and data definitions. These tables were expanded to include CIHI data from the five intervening fiscal years (1996/97 to 2000/01) and enhanced to include additional age categories, namely neonates (0 to 28 days) and patients 15 to 18 years of age.

The subset of data used to define tertiary care followed the Hay Consulting Group algorithm, as provided to the HSRC. The algorithm is based on a combination of CMGs, case complexity and age groups and results in cases being defined as primary, secondary or tertiary in nature. Tertiary surgical care and pediatric age groups were selected to retrieve data for tertiary pediatric services. In retrieving tertiary pediatric cardiac surgery data, a definition of cardiac services was applied. This definition includes CMG codes 125 to 127; 175 to 195; 200 to 219; 222 to 243; and 250. For the neonatal age group, CMG codes 625 to 628; 630 to 632; 636 to 640; 643 to 647; and 998 were used. These CMG codes were selected with the combination of cardiac surgical principal procedures (Canadian Classification of Surgical Procedures or CCSPs 47.00 to 49.99) to define tertiary neonatal cardiac surgery procedures.

Data retrieval for pediatric transplant procedures were based on a selection of age groups and CCSPs for transplants. Heart transplant is CCSP 49.5; liver transplant is CCSP 62.4 and kidney transplant is CCSP 67.5. Transplant data were captured only for hospitals where a transplant was performed.

Graphs were prepared for selected data to facilitate presentation. Finally, small cell data were noted as '<5' and corresponding totals adapted to range values in order to comply with FOIPPA provisions.

The CMG methodology is designed to aggregate patients with similar clinical and resource utilization characteristics. CMGs are groupings of diagnoses, procedures, age cohorts and co-morbidities, with diagnoses being a principle variable to classify CMGs as a cardiac grouping. For example, a patient with a cardiac procedure will not be included in the cardiac category of CMGs, unless the 'most responsible diagnosis' captured on CIHI abstract is a cardiac diagnosis. Retrieving volumes of cases based on CMGs do not fully account for all patients who may have undergone a cardiac procedure if their most responsible diagnosis was something else.

Consistent with the HSRC, the SPSRC reviewed data with the same parameters in order to build upon the HSRC's work, confirm trending and make recommendations. Unless

otherwise noted, the data presented in both the HSRC's and this report are based on cases (patients) rather than procedures.

One observation that was noted when reviewing the updated data was the presence of tertiary cases in Hamilton and Kingston, for whom the HSRC did not record any cases in 1995/96. In 2000/01, Hamilton and Kingston accounted for 3.3% (21 out of 638) tertiary pediatric cardiac surgery cases (ages 0 to 14). The two centres are reviewing these numbers in order to clarify the types of cases that have been reported to CIHI and whether the activity is related to data coding.

Listed below are the individual CMGs used for retrieving the data for cardiac surgery. As noted previously, this listing was further subjected to parameters for age and level of care (tertiary). The neonatal CMGs were subjected to surgical procedures.

Cardiac and Neonate Case Mix Groups (CMGs)

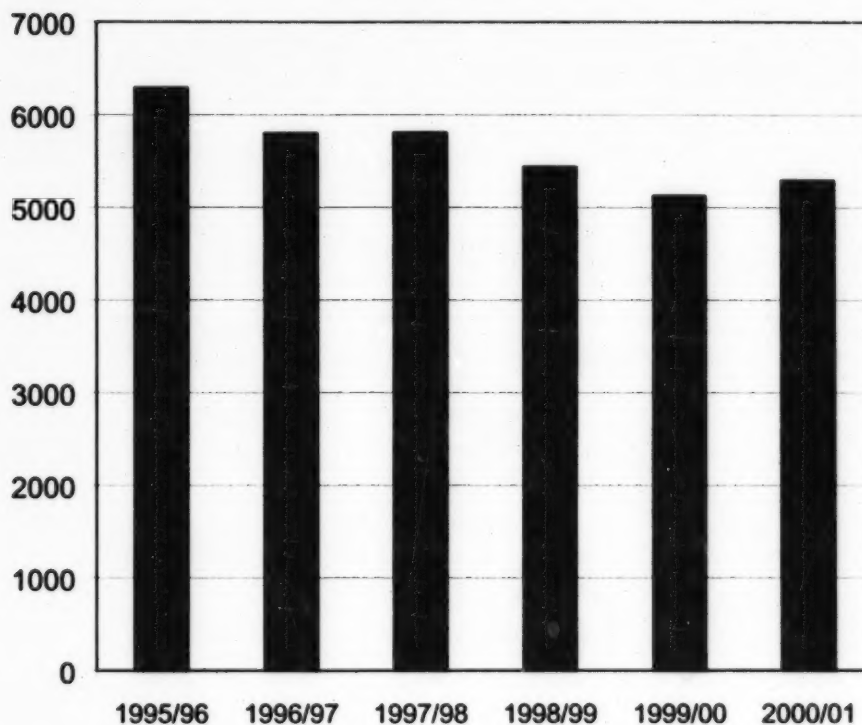
Neonate CMGs in combination with cardiac procedure indicate neonate cardiac patients

CMG	Med/Surg	CMG Description	PC Description
125	S	MAJOR CHEST PROCEDURES	Cardio/ Thoracic
126	S	OTH RESPIRATORY PROC NOCC	Cardio/ Thoracic
127	S	OTH RESPIRATORY PROC CC	Cardio/ Thoracic
175	S	HEART OR LUNG TRANSPLANT	Cardio/ Thoracic
176	S	CRD VLV REP W PUMP W CRD CATH	Cardio/ Thoracic
177	S	CRD VLV REP W PUMP NO CATH	Cardio/ Thoracic
178	S	COR BYPASS W PUMP W CARD CATH	Cardio/ Thoracic
179	S	COR BYPASS W PUMP NO CATH CC	Cardio/ Thoracic
180	S	COR BYPASS W PUMP NOCATH NOCC	Cardio/ Thoracic
181	S	OTH CARDIO PR W PUMP W CATH	Cardio/ Thoracic
182	S	OTH CARDIO PR W PUMP NO CATH	Cardio/ Thoracic
183	S	MAJ CARDIO PR NO PUMP W CATH	Cardio/ Thoracic
184	S	MAJ CARDIO PR NO PUMP NO CATH	Cardio/ Thoracic
185	S	PERM PACEMAKER IMP/CARD COMP	Cardio/ Thoracic
186	S	PERM PACEMAKER WITH CC	Cardio/ Thoracic
187	S	PERM PACEMAKER NO CC	Cardio/ Thoracic
188	S	PTCA WITH COMP CARD CONDITION	Cardio/ Thoracic
189	S	PTCA WITH CC	Cardio/ Thoracic
190	S	PTCA NO CC	Cardio/ Thoracic
191	S	TEMP PACEMAKER IMP WITH CC	Cardio/ Thoracic
192	S	TEMP PACEMAKER IMPLANT NO CC	Cardio/ Thoracic
193	S	CARDIAC PACEMAKER REPLACE	Cardio/ Thoracic
194	S	MIN CARDIO PROC NO PUMP CC	Cardio/ Thoracic
195	S	MIN CARDIO PROC NO PUMP NO CC	Cardio/ Thoracic
250	S	EXTENSIVE G.I.PROCEDURES	Cardio/ Thoracic
200	M	AMI,ANG,CATH W SHOCK/PUL EMB	Cardiology
201	S	AMI WITH CARD CATH WITH CHF	Cardiology
202	S	AMI W CARD CATH W VENT TACH	Cardiology
203	S	AMI W CARD CATH WITH ANGINA	Cardiology
204	S	AMI WITH CATH NO SP CARD COMP	Cardiology
205	M	AMI NO CARD CATH WITH CHF	Cardiology
206	M	AMI NO CARD CATH W VENT TACH	Cardiology
207	M	AMI NO CARD CATH WITH ANGINA	Cardiology
208	M	AMI NO CATH AGE > 70 WITH CC	Cardiology
209	M	AMI NO CATH AGE>70NOCC,AGE<70	Cardiology

210	S	UNS ANGINA W CATH W CARD COMP	Cardiology
211	S	UNS ANGINA W CATH NO CRD COMP	Cardiology
212	M	UNS ANGINA NO CATH W CRD COMP	Cardiology
213	M	UNS ANGINA NO CATH AGE>70 CC	Cardiology
214	M	UNS ANGINA NOCATH,>70NOCC,<70	Cardiology
215	S	CARDIAC CATH WITH CHF	Cardiology
216	S	CARDIAC CATH WITH VENT TACH	Cardiology
217	S	CARDIAC CATH WITH UNST ANGINA	Cardiology
218	S	CARD CATH NO COND OR LOS <4	Cardiology
219	M	ENDOCARDITIS	Cardiology
222	M	HEART FAILURE AGE > 70 CC	Cardiology
223	M	HEART FAILURE,>70NOCC,<70CC	Cardiology
224	M	HEART FAILURE AGE < 70 NOCC	Cardiology
225	M	HYPERTENSIVE HEART DISEASE	Cardiology
226	M	OTH CIRC DX AGE > 70 CC	Cardiology
227	M	OTH CIRC DX,>70NOCC,<70CC	Cardiology
228	M	OTH CIRC DX AGE < 70 NOCC	Cardiology
229	M	ATHEROSCLEROSIS AGE > 70 CC	Cardiology
230	M	ATHEROSCLEROS, >70NOCC,<70CC	Cardiology
231	M	ATHEROSCLEROS,<70NOCC (MNRH)	Cardiology
232	M	ACQUIRED VALV DIS (MNRH)	Cardiology
233	M	HYPERTENSION (MNRH)	Cardiology
234	M	CONGENITAL CARD DISORD(MNRH)	Cardiology
235	M	ANGINA PECTORIS, AGE > 70 CC	Cardiology
236	M	ANGINA PECTORIS,>70NOCC,<70	Cardiology
237	M	ARRHYTHMIA AGE > 70 CC	Cardiology
238	M	ARRHYTHMIA AGE >70NOCC,<70CC	Cardiology
239	M	ARRHYTHMIA AGE < 70 NOCC	Cardiology
240	M	SYNCOPE & COLLAPSE,>70CC	Cardiology
241	M	SYNCOPE/COLLAPSE, >70NOCC,<70	Cardiology
242	M	CHEST PAIN AGE > 70 CC	Cardiology
243	M	CHEST PAIN AGE >70NOCC, <70	Cardiology
625	M	NEONATES WEIGHT <750 GRAMS	Neonatology
626	M	NEONATES WEIGHT 750-999 GRAMS	Neonatology
627	M	NEO,1000-1499,CATASTROPHIC DX	Neonatology
628	M	NEO,1000-1499,NO CATASTRPH DX	Neonatology
630	M	NEO,1500-1999,CATASTROPHIC DX	Neonatology
631	M	NEO,1500-1999,MAJOR PROBLM DX	Neonatology
632	M	NEO,1500-1999,MOD,MIN,NO PROB	Neonatology
636	M	NEO,2000-2499,CATASTROPHIC DX	Neonatology
637	M	NEO,2000-2499,MAJOR PROBLM DX	Neonatology
638	M	NEO,2000-2499,MODERATE PROBLM	Neonatology
639	M	NEO,2000-2499,MINOR PROBLM DX	Neonatology
640	M	NEO,2000-2499,NO PROBLEM DX	Neonatology
643	M	NEO,WT>2500GM,CATASTROPHIC DX	Neonatology
644	M	NEO,WT>2500G,MAJOR PROBLEM DX	Neonatology
645	M	NEO,WT>2500G,MODERATE PROBLEM	Neonatology
646	M	NEO,WT>2500G,CAESAREAN DELIVR	Neonatology
647	M	NEO,WT>2500G,MINOR PROBLEM DX	Neonatology
998	M	NEONATE - SHORT STAY TRIM	Neonatology

APPENDIX 5 -- Graph 1
Tertiary Pediatric Surgical Cases in Ontario
(0-14, excl. Neonates)

Graph 1: Tertiary Pediatric Surgical Cases in Ontario
(0-14, excl. Neonates)



APPENDIX 6

Table 2: Tertiary Paed. Cardiac Surgery Procedures Separation: 7-Jan-02

Year	Age Group	London LHSC	Ottawa CHEO	Toronto HSC	All Other Hospitals	Total
1995/96	HSRC Report					
	0-4 (*)	21	45	233	<5	300 to 303
	5-9	22	32	194	5	253
	10-14	18	21	120	13	172
	Total 0-14	61	98	547	22 to 25	725 to 728
1996/97	0-4 (*)	45	75	385	6	511
	5-9	21	25	88	7	141
	10-14	6	16	70	13	105
	Total 0-14	72	116	543	26	757
	Neonates	<5	5	11	0	16
	15-18	16	11	41	49	117
1997/98	0-4 (*)	43	83	391	9	526
	5-9	9	14	101	<5	125 to 128
	10-14	12	22	92	6	132
	Total 0-14	64	119	584	16 to 19	773 to 776
	Neonates	7	6	9	0	22
	15-18	9	16	34	57	116
1998/99	0-4 (*)	65	67	314	8	454
	5-9	13	22	85	<5	121 to 124
	10-14	10	11	79	17	117
	Total 0-14	88	100	478	26 to 29	667 to 669
	Neonates	<5	<5	7	0	9 to 15
	15-18	11	16	48	50	125
1999/2000	0-4 (*)	62	65	317	11	455
	5-9	9	20	85	<5	115 to 118
	10-14	10	18	58	<5	87 to 90
	Total 0-14	81	103	460	13 to 19	657 to 663
	Neonates	<5	<5	11	0	13 to 19
	15-18	15	9	46	67	137
2000/01	0-4 (*)	61	65	305	9	440
	5-9	9	9	68	<5	87 to 90
	10-14	13	16	68	12	109
	Total 0-14	83	90	441	22 to 25	636 to 639
	Neonates	<5	<5	18	0	20 to 26
	15-18	17	10	51	71	149

Percentage change 95/96 to 00/01

0-14

36.1%

-8.2%

-19.4%

12.2%

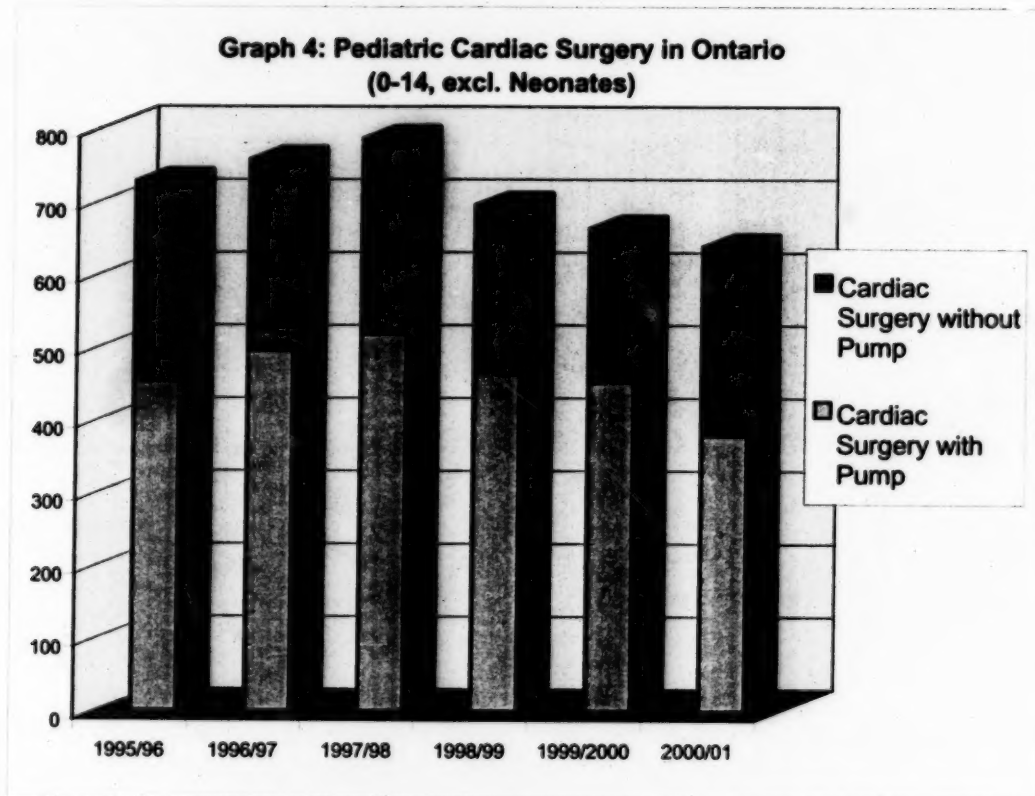
Average annual cases

95/96 to 00/01	0-14	74.8	104.3	508.8
96/97 to 00/01	Neonate to 18	94.6	121.4	

Note: (*) excluding neonates

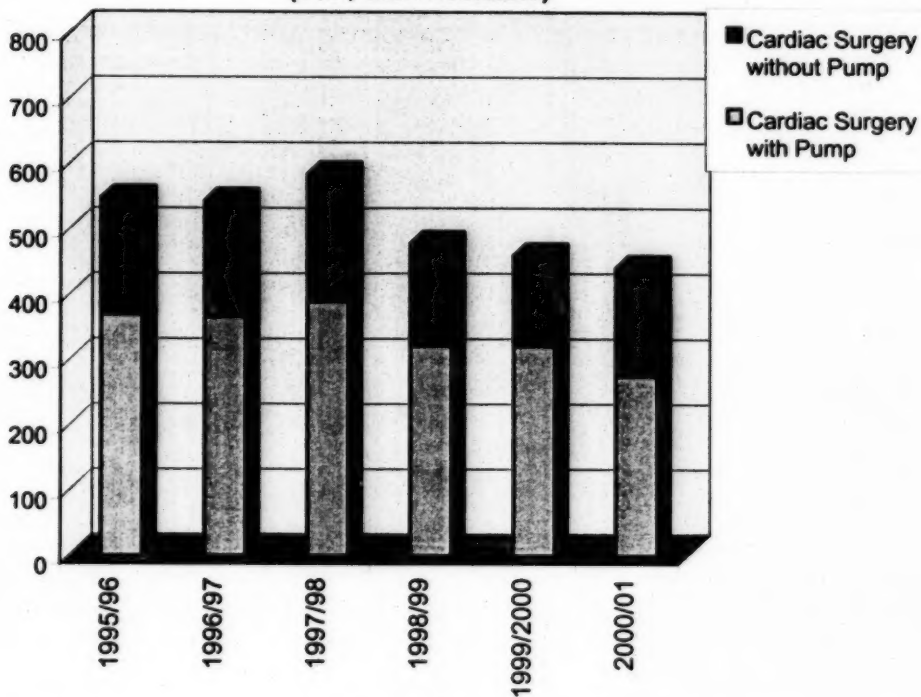
** Ottawa: includes The Ottawa Hospital (former Civic, General) and The Ottawa Heart Institute;
London HSC includes London St Joseph's; Hamilton HSC includes Hamilton St Joseph's

APPENDIX 7 -- Graph 4
Pediatric Cardiac Surgery in Ontario
(0-14, excl. Neonates)

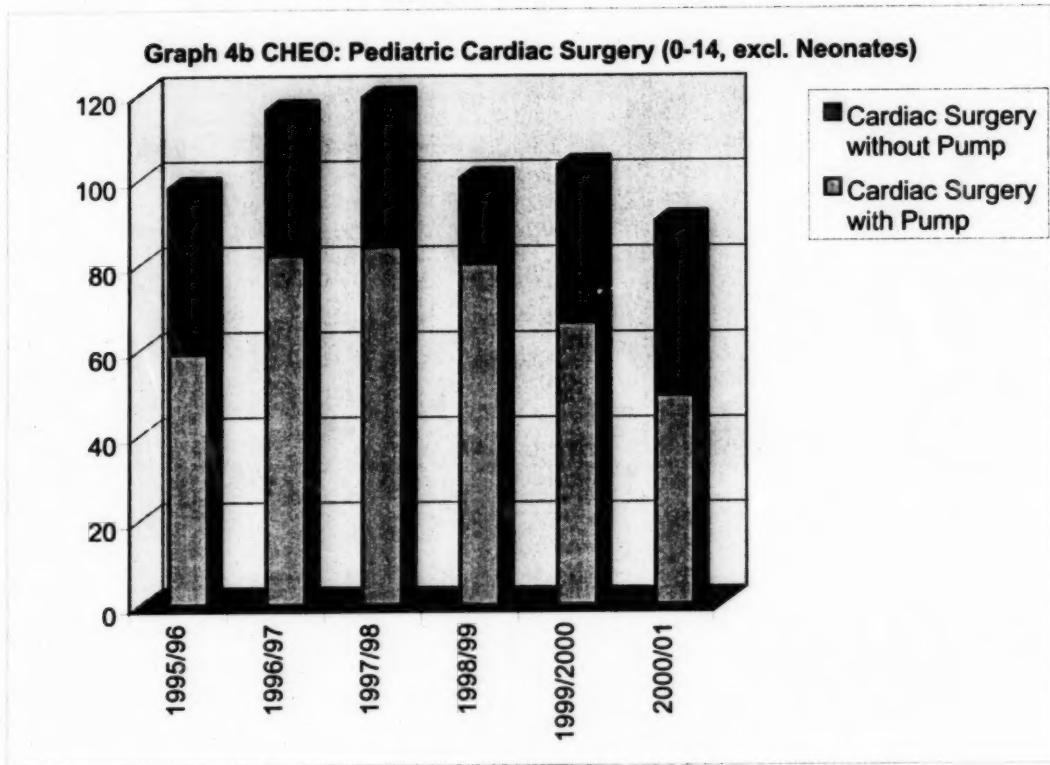


APPENDIX 7 --Graph 4a
Hospital for Sick Children: Pediatric Cardiac Surgery
(0-14, excl. Neonates)

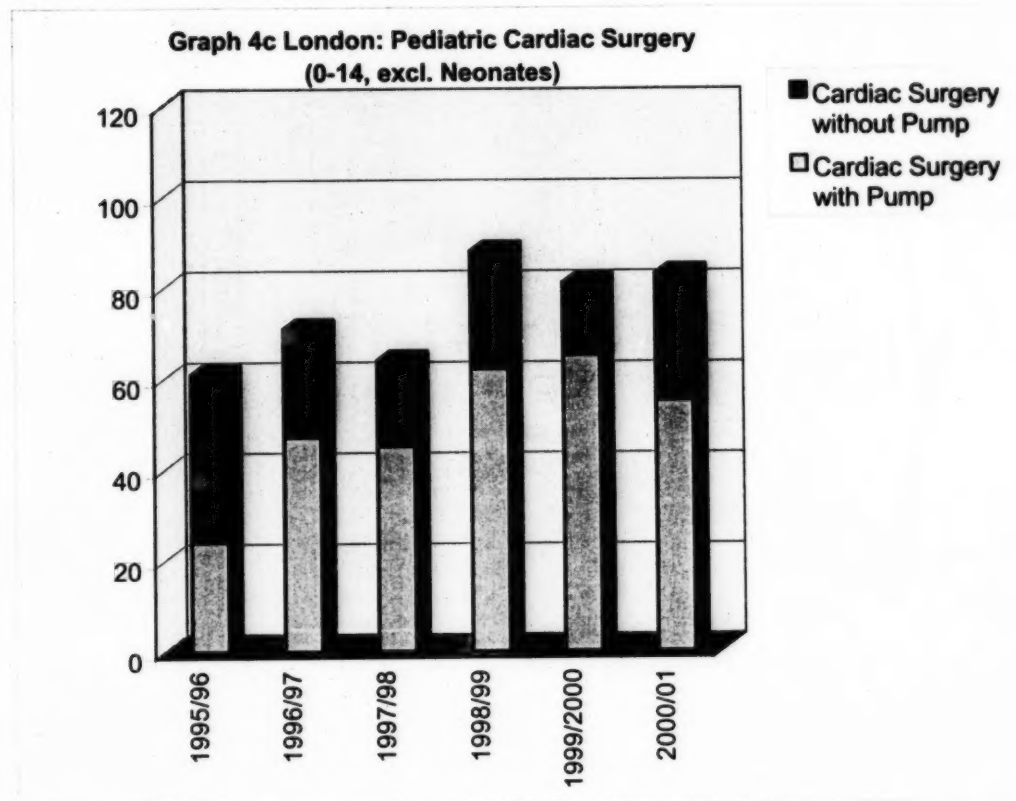
Graph 4a Hospital for Sick Children: Pediatric Cardiac Surgery
(0-14, excl. Neonates)



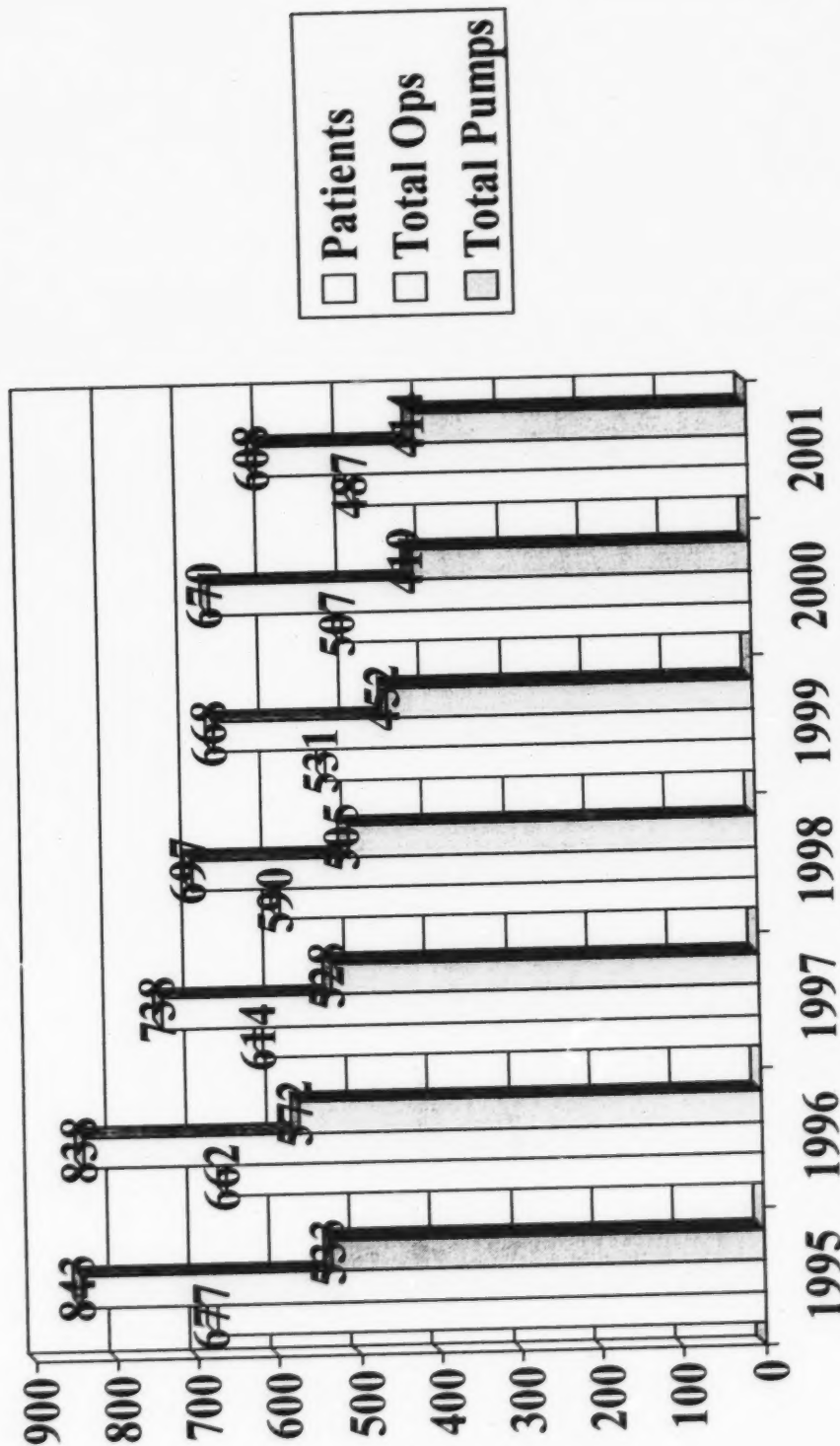
APPENDIX 7 -- Graph 4b
CHEO: Pediatric Cardiac Surgery (0-14, excl. Neonates)



APPENDIX 7 -- Graph 4c
London: Pediatric Cardiac Surgery
(0-14, excl. Neonates)



APPENDIX 8
Cardiac database maintained by HSC
HSC Cardiac Cases



Patients - newborn to 18yrs

Total Ops - total number of pump and non pump cases done in the OR and CCU

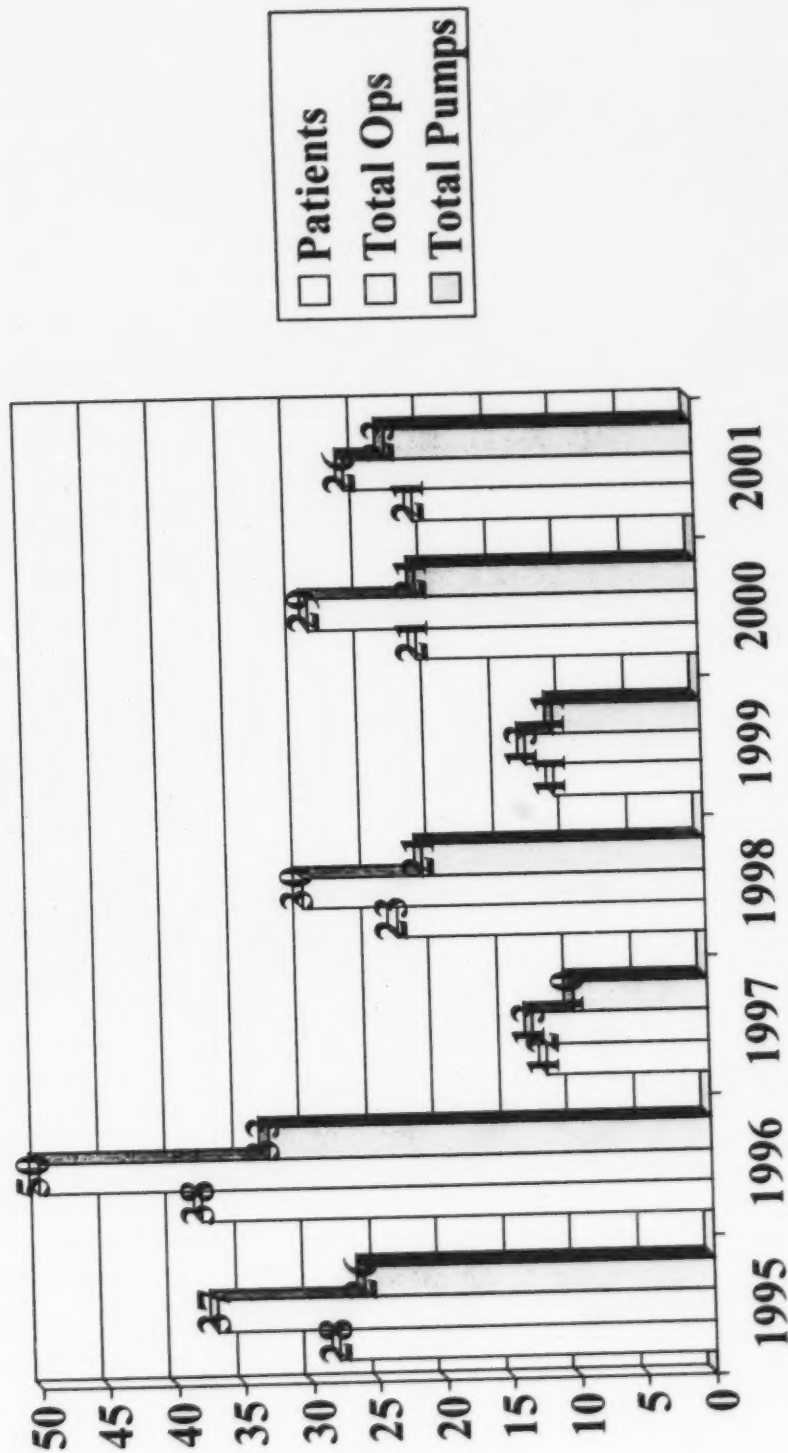
Total Pumps - operations requiring cardiopulmonary bypass

- included in the total operations number

- difference between "Total Ops" and "Total Pumps" are the cases done in OR not requiring bypass (Coarctation, sternal closures)

The patient number is generally less than the operation total, as some patients require several operations.

APPENDIX 9
Cardiac database maintained by HSC
HSC Data Base: HSC Referrals from Ottawa/Eastern Ontario



Patients - newborn to 18yrs

Total Ops - total number of pump and non pump cases done in the OR and CCU

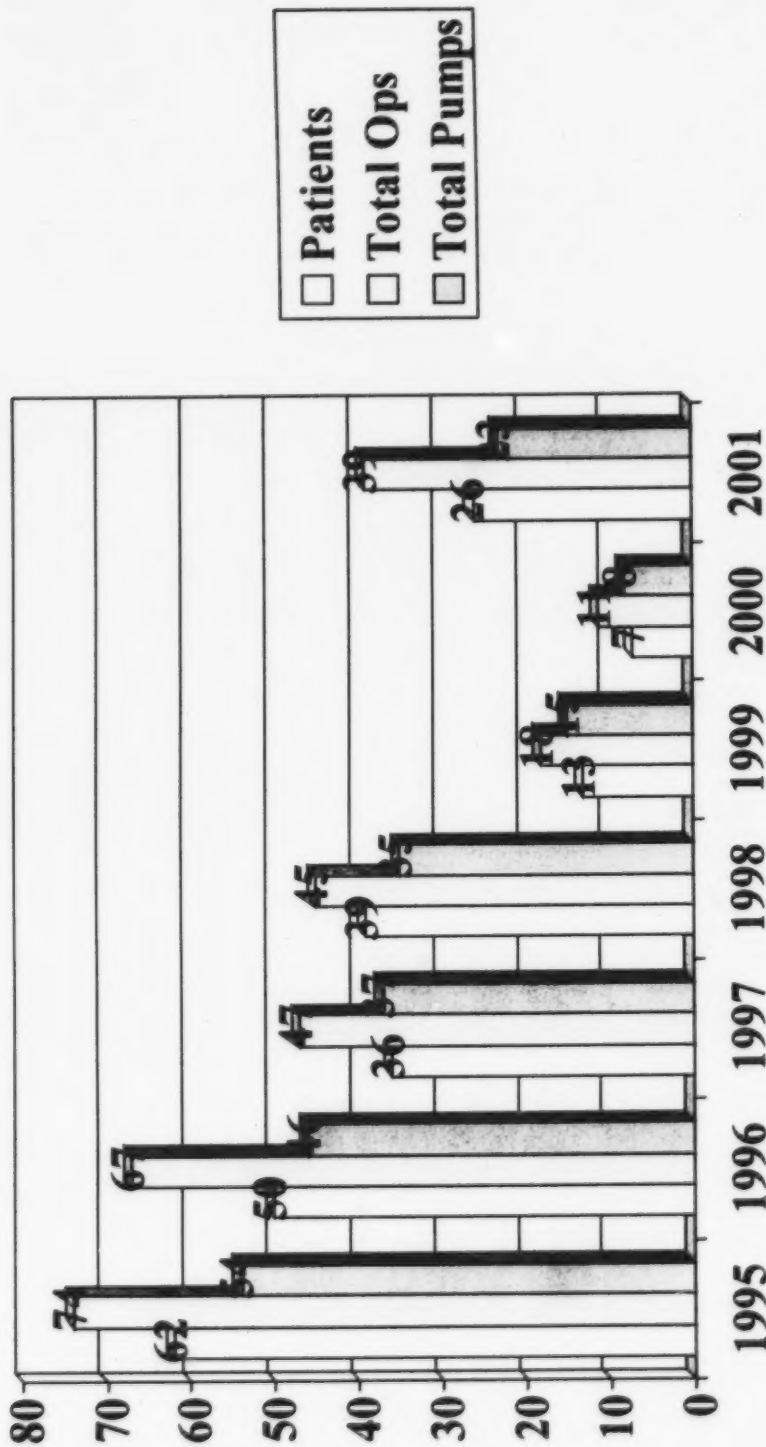
Total Pumps - operations requiring cardiopulmonary bypass

- included in the total operations number

- difference between "Total Ops" and "Total Pumps" are the cases done in OR not requiring bypass (Coarctation, sternal closures)

The patient number is generally less than the operation total, as some patients require several operations.

APPENDIX 10
Cardiac database maintained by HSC
HSC Data Base: HSC Referrals from London/Western Ontario



Patients - newborn to 18yrs

Total Ops - total number of pump and non pump cases done in the OR and CCU

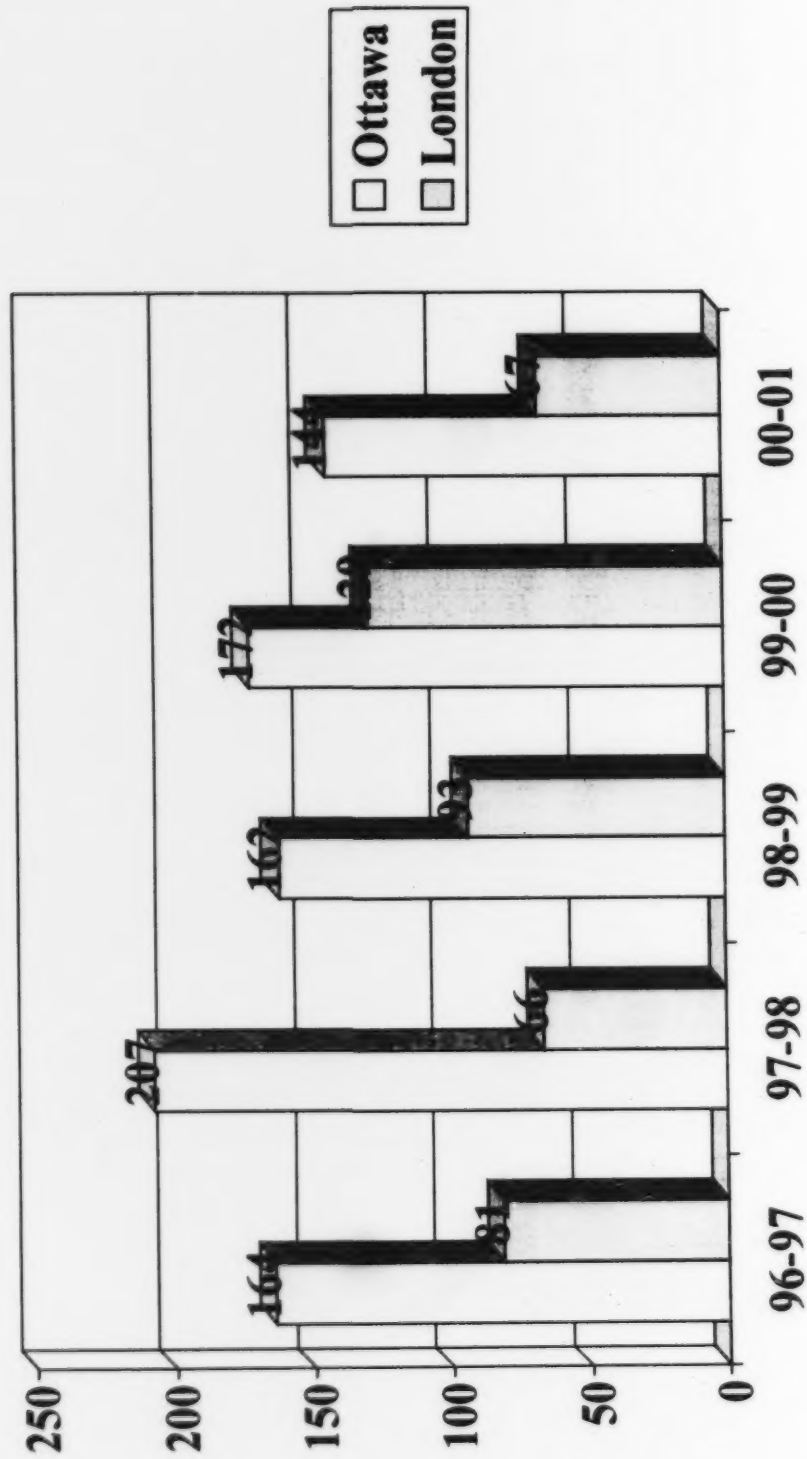
Total Pumps - operations requiring cardiopulmonary bypass

- included in the total operations number

- difference between "Total Ops" and "Total Pumps" are the cases done in OR not requiring bypass (Coarctation, sternal closures)

The patient number is generally less than the operation total, as some patients require several operations.

APPENDIX 11
Cardiac database maintained by HSC
Cardiac Cases in Ottawa and London



Provided by Ottawa & London's Coordinators